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Title	Will the creation of an adolescent cancer centre lead to improved outcomes in Yorkshire?
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Will the creation of an adolescent cancer centre lead to improved outcomes in Yorkshire?

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Declaration

I declare that the work contained in this thesis is entirely my own, with the exception of part of the Yorkshire part of the survival analysis. The Northern survival analysis is entirely my own work

I have received assistance and advice from the following for the execution of the Yorkshire part of the survival analysis:

Richard Feltbower, Roger Parslow and Patricia MacKinney.

My role in the study was as follows:

The initiation of the study, the literature review, the collection and collation of the data from the North Children's Tumour Registry and the Northern and Yorkshire Cancer Registry. I undertook the data analysis, prepared the tables and graphs. I wrote the report in its entirety.

I designed the qualitative study, gained ethical approval and carried out all the interviews described in this thesis.

I am also grateful for the assistance of Professor Freda Alexander who acted as my tutor for the work and Dr Ian Lewis for providing general advice and support. I am also grateful to Ms Sue Morgan for her assistance in setting up the interviews on the paediatric oncology ward at St James' Hospital, Leeds.

I am grateful to Mrs Val Saunders of the Northern and Yorkshire Cancer Registry and Information Service for providing the data for this study and to Dr Louise Parker from the Northern Children's Tumour Registry for providing similar data for the former Northern region.

I would like to thank the young people and their parents who were prepared to be interviewed for this study, the healthy young people at Richmond School and their headmaster, Mr Jim Jack and Head of Sixth Form, Mr Keith Allen for permitting the interviews to take place. I am also grateful to the consultants at the Friarage Hospital in Northallerton who were prepared to be interviewed.

I would like to thank Professor Peter Selby and Professor Bob Haward for providing the stimulus to undertake the work. I would also like to thank my employer, North Yorkshire Health Authority for allowing me to undertake this work and in particular, the support of Professor Mark Baker, Medical Director.

Dr John Robert Wilkinson
8 June, 2001

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1. Abstract

Objective: To assess the need for an adolescent cancer unit to serve the population in Yorkshire.

Design: An epidemiological review of the data from two sources in the Northern and Yorkshire Region. A qualitative methodology was employed to assess the views of patients, healthy adolescents and staff on a unit away from the centre dealing with adolescents, on the benefits of a centralised adolescent unit.

Interventions: None

Results: Routine cancer registration data on 2411 adolescents registered with cancer between 1985 and 1994 were collected from the Northern and Yorkshire Cancer Registry and the Northern Children's Tumour Registry. The data related to 1375 patients in the former Yorkshire Region and 1036 patients in the former Northern Region. Incidence data are presented for the two regions. Survival differed significantly between parts of Yorkshire but this did not appear to relate to place of treatment or social class. In the former Northern Region some differences were also apparent in survival, but the content of the data did not allow analysis by social class. However, in both instances survival appeared to be better in areas close to the cancer centre which was counter-intuitive to the expectations based on the known social class gradients in the former Yorkshire and Northern Regions. The qualitative studies discovered the specific needs of adolescents with cancer (e.g. the importance of peer group support and maintaining their education) and suggested that there could be benefit from centralised, specialised management. However, there were considerable potential flaws in the data which may render such a conclusion as debatable.

Conclusions: This study adds weight to the proposal for the development of an adolescent cancer unit in Yorkshire, however, this study is by no means conclusive because of the absence of available data to answer this question. The reasons why, overall support should be given to create an adolescent unit fall into four categories: philosophical (the need to provide services which recognise the specific needs of adolescents), qualitative (the ability of specialist units to provide a higher quality of care), pragmatic (the ability to concentrate specialist skills in one location), and improved outcome, this study suggests that outcome, and survival in particular differs may differ significantly according to where people live, and that this may be related to the type of care they receive. Further studies are needed to explain the apparent survival differences in the region.

2. Background and Introduction

2.1 The proposal to establish an Adolescent Cancer Unit

This piece of work originated from a proposal from the paediatric and medical oncologists at St. James' Hospital in Leeds to establish an Adolescent Cancer Unit. Such units have been established in other parts of the country. Their creation has been encouraged by grants from the Teenage Cancer Trust[1]. Such grants have been made available for the capital costs associated with such developments and have therefore covered the costs of buildings and equipment. In some instances, running costs have been provided for a limited number of years. The Teenage Cancer Trust suggests in their publicity material that "treating young people with cancer in specialist Teenage Cancer Trust Units can improve recovery rates by 15%". The units themselves are designed to provide an environment appealing to teenagers as well as full emotional, social, psychological, educational and recreational support. They are also designed to support parents, relatives and friends as well as the patients themselves.

The Teenage Cancer Trust estimates that the average annual running costs of a specialist cancer unit for teenagers is likely to be £500,000. The trust estimates that 20 such units are required in the U.K. A business case from the

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[1] Teenage Cancer Trust, Kirkham House, Kirkham Place, 54a Tottenham Court Road, London. W1P 9RF

Leeds Teaching Hospitals Trust states that the cost in the first year will be £1.09 Million[2]. The details of this proposal are considered further in chapter 9.

The Teenage Cancer Trust has pointed out the difficulties of the management of teenagers with cancer. Unless they are managed in special units, they are likely to be managed either in a children's ward ("with bunnies decorated on the walls") or alongside the elderly - isolated from people of their own age.

The proposal from the Leeds Trust only includes a small start up cost, the bulk of which, it is anticipated will be met from charitable sources. Whilst not decrying the proposal to develop special units for teenagers with cancer, it is a stark fact of life that if the National Health Service invests in these developments, this will occur at the expense of other developments. It is therefore essential to be clear what benefits will accrue from this type of development, in order that investment decisions can be taken to ensure that the limited funds available to the NHS are spent to the best effect.

2.2 The Role of a public health physician

This work has been undertaken from the perspective of a public health physician working in a health authority (the role and function of health authorities is discussed in the following section). Public health physicians are trained to be able to give advice and to make decisions on such questions.(1). Their skills in epidemiology, management, economics are particularly relevant in this area. Public health physicians are also unique in bringing these skills

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[2] Leeds Teaching Hospitals Trust. The Business Case for Adolescent Cancer Services. 1999

together with a background of medical training which enables them to understand and relate directly to some of the complex clinical issues involved in such an area as teenage cancer.

Most public health physicians work in health authorities, although some work in specialist academic units, and some in the Regional Offices and in the National Health Service Executive of the Department of Health. This places the public health physician in a position of responsibility working in situations, where decisions about major new investments such as the management of teenage cancer are currently made and are likely to be made in the foreseeable future.

2.3 Role and functions of health authorities

Under the 1992 NHS Act, Health Authorities had the following responsibilities:

- To assess the health needs of their populations

- To commission services to meet the needs of those individuals in those populations

At the outset of the National Health Service in England, Regional Hospital Boards were created in 1948 around the major teaching centres. Therefore in 1948, the Leeds and Newcastle Regional Hospital Boards were created. In 1974, these became Regional Health Authorities. Between 1974 and 1990,

Regional Health Authorities were responsible for the planning and provision of specialist services such as specialist cancer services. In 1990 the then Conservative Government, in an attempt to stem health service expenditure, created what was to become the internal market. NHS Trusts were formed which became responsible for the delivery of services (providers) and health authorities became responsible for commissioning of those services. Money flowed between the health authorities and trusts by means of 'contracts'.

There are approximately 100 health authorities in England. Health Authorities serve populations between 250,000 and 1 million and are responsible for primary, secondary and tertiary health services.

Gradually, the Regional Health Authorities were also required to divest themselves of their purchasing function to health authorities. This in itself created difficulties because there was suddenly no regional strategic body, nor the wherewithal to ensure that a common approach was taken to the purchasing of specialist services. Regional Health Authorities existed until 1994. After the abolition of regional health authorities in 1994, it became very difficult to co-ordinate the development of regional specialist services. No individual health authority had the lead, not all health authorities had the same priorities, and some health authorities were intent on dis-investing in what they saw as large greedy teaching hospitals.

This led to great dissatisfaction amongst those working in large teaching centres who depended on a number of health authorities for their funding. Consequently, regional specialist services in the early 1990s suffered under

investment, and at best, fragmented development. It was not clear how developments occurred, who would take responsibility for planning them and perhaps most importantly, how they would be funded.

In Yorkshire, the chief executives of health authorities decided to join together to commission these specialist services (under what was to become the M6 arrangements - there were six health authorities in Yorkshire). This arrangement had a shaky start while chief executives gained confidence in one another for an arrangement where to all intents and purposes, they were allowing their colleagues to commit resources on their behalf. Each health authority in Yorkshire took on responsibility for one or more regional specialist services. North Yorkshire Health Authority had already developed a degree of expertise in cancer, and it was therefore not surprising when North Yorkshire health Authority was asked to take on the commissioning of specialist cancer services.

Subsequent to the defeat of the Conservative Government in 1997, the Labour Government announced that the role of health authorities was to change (2). This is largely because of the creation of primary care groups which are taking over the responsibility of commissioning health services from health authorities. However, as far as specialist cancer services are concerned, it is likely that these will continue to be commissioned by health authorities working on behalf of other health authorities in the role of specialist commissioner.

2.4 The role of North Yorkshire Health Authority

North Yorkshire Health Authority is a health district in the Northern and Yorkshire Region, sited in the North of England. It is one of thirteen health authorities in the Northern and Yorkshire Region (see maps). It was only in 1994, that the Northern and Yorkshire Region was created from parts of the former Northern and Yorkshire Regions. This was done at a time when the former Regional Health Authorities were abolished and Regional Offices of the NHS Executive were created.

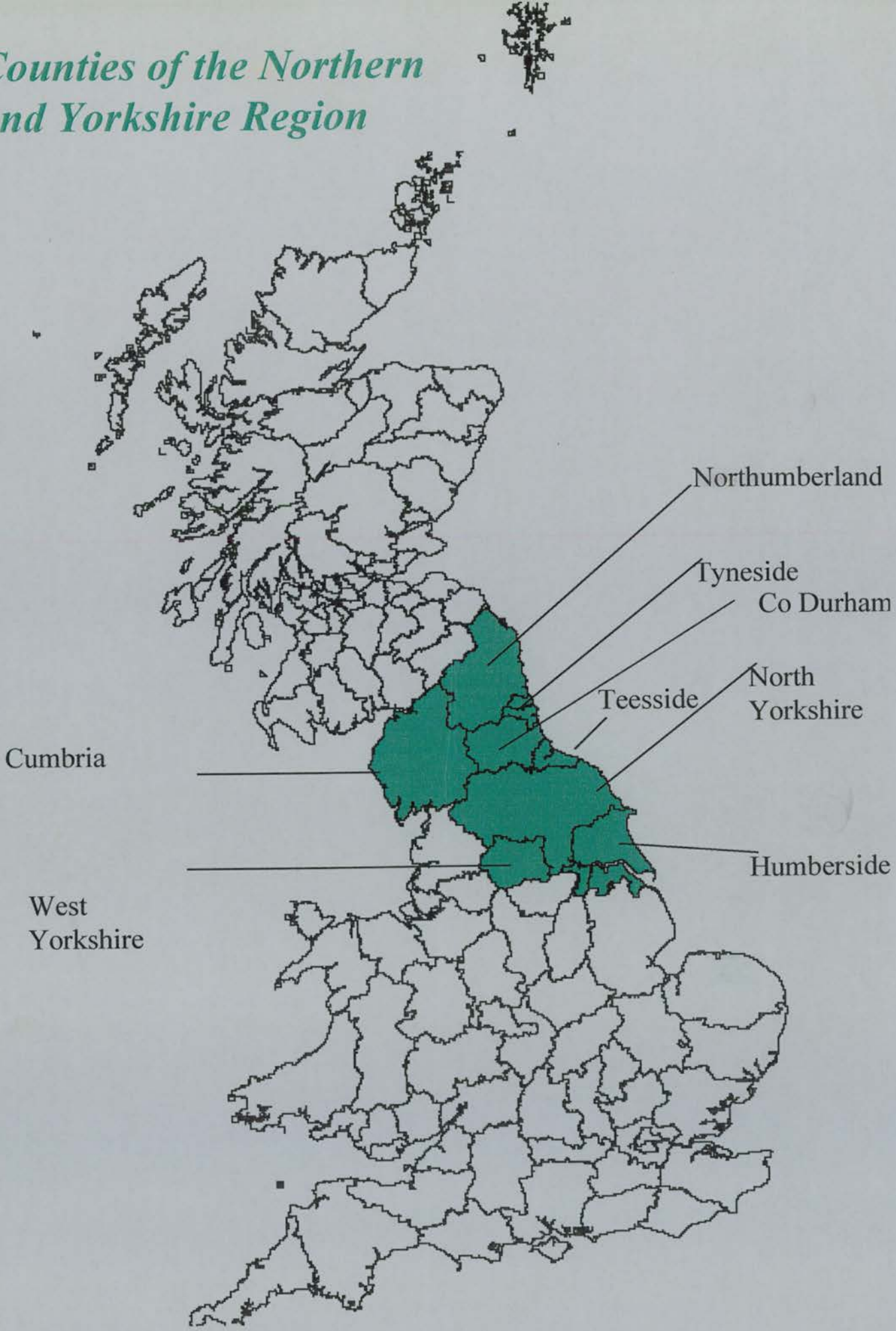
North Yorkshire Health Authority, by which the author is employed, acts in the role of specialist commissioner for cancer services in Yorkshire. It is likely, that in at least the short term to medium term, these arrangements will continue.

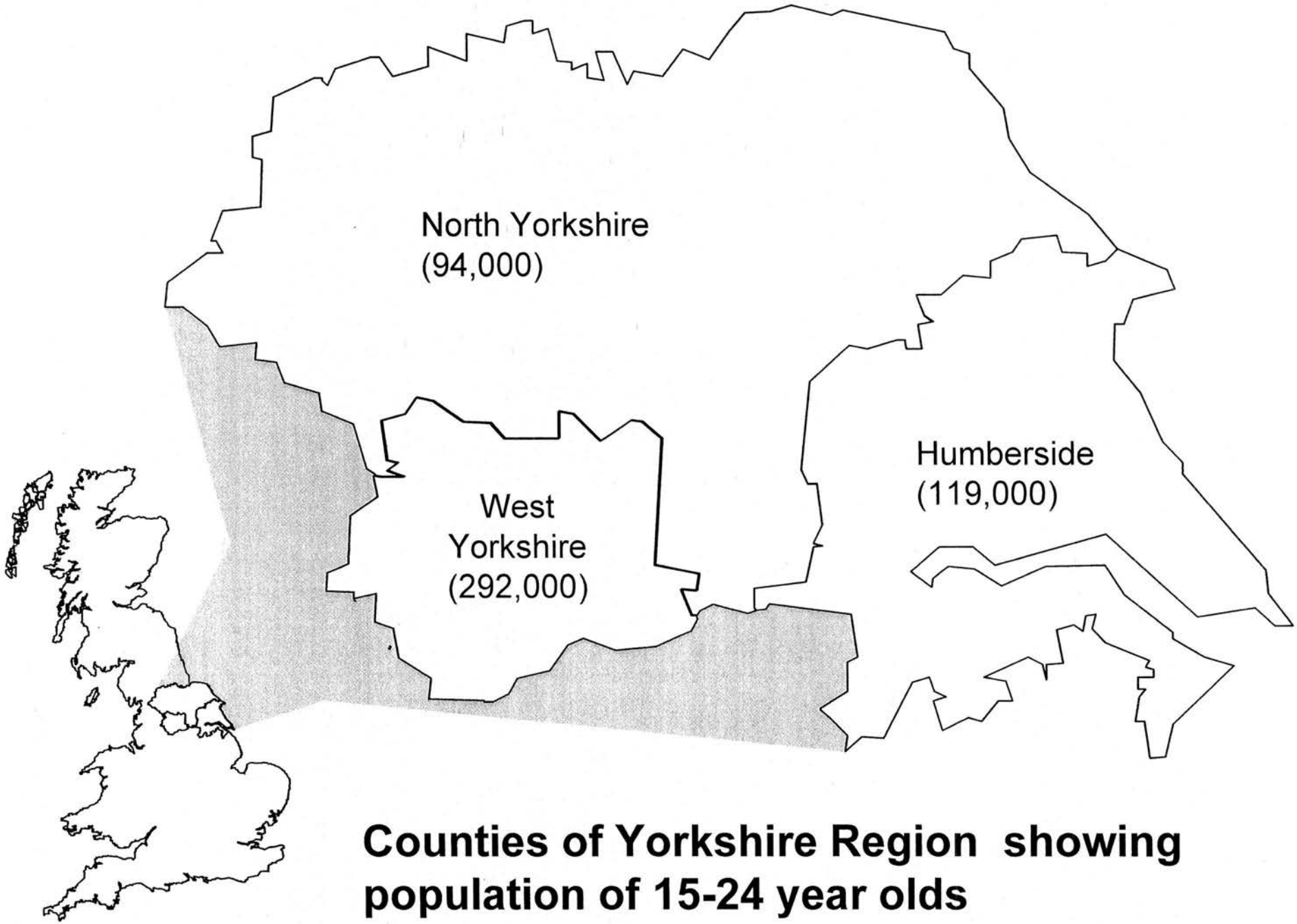
2.5 The aims of this project and the hypotheses

2.5.1 Aims of the project

The development of cancer services for adolescents quickly emerged as a proposal for further funding. The clinicians in the cancer centre in Leeds were keen to develop a cancer unit for adolescents. There were similar moves in Newcastle. Clinicians in both Leeds and Newcastle were receiving considerable support and encouragement from the Teenage Cancer Trust. This trust was keen to provided capital funds for the provision of cancer centres for adolescents. The problem for the health authorities was that these centres have potentially high running costs, and before embarking on such a development in

Counties of the Northern and Yorkshire Region





Counties of Yorkshire Region showing population of 15-24 year olds

Yorkshire, it was agreed that further investigation should be carried out. This study formed the basis of this work.

The purpose of this piece of work was, therefore to contribute to the debate on the future of cancer services for adolescents in Yorkshire.

A small unit had been established based in an existing ward at St James Hospital in Leeds, for young people with cancer, but this did not have all the features of an adolescent cancer unit which would be provided from a fully-fledged unit

At the same time, it became apparent in the early stages of the work, that comparisons between the situation in the former Northern and Yorkshire Regions might also be of value, with the recent creation of an adolescent cancer unit in Newcastle.

As adolescent cancer is relatively rare it was decided that the needs of Young People with cancer should be assessed across the whole of the new Northern and Yorkshire Region.

The work therefore, contains two main components:

1. A needs assessment of young people with cancer using standard descriptive epidemiological techniques. The study will describe in detail, the incidence of cancer in young people across the region. Data will be presented showing the

incidence by geographical location, by cancer type. Survival data for the both Northern and Yorkshire part regions will be presented.

2. A qualitative piece of work examining the needs of young people with cancer. The aim of this part of the work is to delineate the features of cancer care in adolescents, which is deemed to be important.

2.5.2 Hypotheses

In summary this study aims to test a number of hypotheses. These are as follows:

1. That place of treatment results in improved survival
2. That the incidence of cancer in 10-24 year olds does not differ across the Northern and Yorkshire Region
3. That the quality of care which can be offered by specialist teenage units is no better than that offered by smaller, local hospitals.

2.6 Treatment of adolescents with cancer in the Northern and Yorkshire Region

Compared with the United States, there is very little attention paid to the use of health services by adolescents (3). In a survey carried out in 1998 in a selection of English, Scottish and Welsh Health Authorities and Boards, it was found that adolescents aged 12 to 19 occupied an average of 18 inpatient beds and 2.2 day case beds in a district general hospital serving a population of 250,000.

The current pattern of treatment of adolescents in Yorkshire and the Northern region is described below (personal communication Professor Kevin Windebank, Dr. Ian Lewis).

Certain cases tend to be managed at national centres. This applies most specifically to malignant bone tumours which are almost exclusively referred to Birmingham. Choriocarcinoma is managed at a specialist unit in London. Brain tumours are managed in the neurosurgical departments in the region based in Middlesbrough, Newcastle, Leeds and Hull.

There is some variation in how young people with lymphomas and leukaemias are managed. Almost all leukaemias are referred to haematologists in the major centres of the region (Middlesbrough, Newcastle, Leeds and Hull), and managed according to British Committee for Standards in Haematology (4). However, the management of lymphomas is more variable with some patients being managed in local district hospitals by haematologists. Currently the newly established networks of clinicians are setting up systematic methods of collecting these data, but currently more systematic information is not available. Routinely collected hospital statistics are currently inadequate to provide insight into the management patterns of cancer in adolescents in the region – the main deficiency being the variability in completeness of clinical coding.

At St James' Hospital in Leeds, which acts (in Yorkshire) as the regional centre for the management of childhood malignancy, a small 4-bedded bay for adolescents has been created in the children's ward act as a focus for the

treatment of adolescents. At the Royal Victoria Infirmary in Newcastle, a specialist adolescent unit has been established with the capital cost provided by the Teenage Cancer Trust.

Radiotherapy for adolescents with cancer is provided at radiotherapy centres in Leeds, Newcastle, Hull and Middlesbrough. In all instances, radiotherapy is provided in a separate hospital from where other treatment is carried out.

3. The Health of Adolescents

3.1 The concept of adolescence

The Oxford English Dictionary defines adolescent as: (someone) between childhood and adulthood (5).

Although adolescence was not recognised historically, characteristics of today's teenagers can be identified in the writings of the ancient Greeks (6):

Our youth love luxury; they have bad manners, contempt for authority, they show disrespect for elders and love chatter in place of exercise.

When Keats was twenty-three, he wrote in Endymion(7):

'*The soul is in ferment, the character undecided, the way of life uncertain, the ambition thickest*'

In lay terms, adolescence(8) is described as a stage of maturation between childhood and adulthood. The term denotes the period from the beginning of puberty to maturity; it usually starts at about age 14 in males and age 12 in females. The transition to adulthood varies among cultures, but it is generally defined as the time when individuals begin to function independently of their parents.

Not all writers have always accepted that there is such a period of time in life. In the nineteenth century, children were treated as adults as soon as they were old enough to work or leave school. John Locke (9) wrote 'The sooner you treat him as a man, the sooner he will be one'. In 1939 the headmaster of Rugby School was reported as saying 'the change from childhood to manhood.... ought to be hastened; and it is a sin not to hasten it (10).

There are other factors which have lead to an increased recognition of the period of adolescence since that date. These are set out in box 1.1.

Box 1.1 Social Changes leading to the developing concept of adolescence

- The state school system from the 1880s,
- The demands of modern industrial society for workers who have been educated
- The gradual rise in the school leaving age
- Increasing national concern about managing the health of young people and their future reproductive health
- Rising unemployment rates among adults, who prefer young people to be at college and not competing for real jobs
- The growth of commercially driven youth cultures
- Recent reductions in benefits for people under 25, housing shortages delaying move away from the parental home

Source: Alderson (11)

3.1.1 Physical Development

Changes in physical appearance are very noticeable at this period of life. Many of the changes are due to hormonal activity. The pituitary gland begins to secrete an increased level of follicle stimulating hormone and lutenising hormone. These two hormones have a direct effect on the gonads and have a secondary effect throughout the body and lead to the development of secondary sexual characteristics. There is also increased secretion of growth hormone at this time resulting in rapid growth. This results in the body becoming close to its adult height and weight in about two years. This growth spurt occurs earlier among females than males, also indicating that females

mature sexually earlier than males. The production of androgens in boys and oestrogens in girls leads to the onset of menstruation in girls and in boys, the production of semen. These hormones also lead to the development of secondary sexual characteristics including facial, bodily, and pubic hair and a deepening voice among males; pubic and bodily hair, enlarged breasts, and broader hips among females.

3.1.2 Intellectual development

Adolescents are developing fast at this time in their lives, though intellectual development is thought to be closely associated with educational input rather than due to physical, including hormonal changes.

3.1.3 Emotional Development

The American psychologist G. Stanley Hall (12) asserted that adolescence is a period of emotional stress, resulting from the rapid and extensive physiological changes occurring at pubescence. Studies by the American anthropologist Margaret Mead (13) however, showed that emotional stress is not inevitable, but culturally determined; she found that difficulties in the transition from childhood to adulthood varied from one culture to another. The German-born American psychologist Erik Erikson (14) sees development as a psychosocial process going on through life.

The psychosocial task of adolescence is to develop from a dependent to an independent person, whose identity allows the person to relate to others in an adult fashion (intimacy). The occurrence of emotional problems varies among adolescents.

3.1.4 Defining adolescence

Adolescence is inevitably an indistinct concept and will vary from individual to individual. There is no universally accepted age limit for adolescents. Most would agree that no individuals could be considered adolescents outwith the age of 10 to 25, but within that age range, many different age criteria are used. The World Health Organisation defines adolescents as being aged between 10 and 19 (15)

Other studies on adolescents, some of which will be described later, consider a different age range for adolescents. Jamison (16) in his study of the psychological impact of cancer in 1985, used the age range 12 – 18. Enskär K and colleagues (17) in a study which looked at ten adolescents with cancer used the age range 13 – 20. Lewis(18) describes adolescence as a flexible concept that encompasses most individuals in the age range of 14 – 22, but can stretch several years in each direction. "Adolescents are both adults and children".

Kuykendall describes the inconsistency of the concept of adulthood. He points out that in England, 16 year olds are allowed to leave school, marry (with parental consent) and legally have sex. They can ride a motorbike, but have to wait until they are 17 to drive a car and 18 to vote and legally drink alcohol. He suggests that the only logical way to describe adolescence is using a developmental approach dividing adolescence into early middle and late stages, and concentrate on what is happening socially, intellectually, emotionally, physically, sexually, and psychologically. Kuykendall describes the

interaction between acute and chronic illness, hospitalisation and terminal admission and adolescence, and states that care givers must be clear about these interactions. (19)

3.1.5 Does it matter?

Probably no one would argue with the extremes. i.e. no one could be considered adolescent outwith the age range 10-25. So far as the health service is concerned; age ranges have been used in a range of specialties and continue to be used. In some areas the use of strict age related criteria has been abandoned. Only a few years ago there were strict age related criteria for admission to coronary care units. In some cases patients were denied admission if they were over the age of 65 years. These policies are gradually changing; this has partly come about with the increasing confidence in the specialism of elderly medicine. However, it is generally recognised that patients should be managed according to needs, rather than to strict age bands.

Similarly in the past, prejudices have been exercised against other groupings in society. For many years, patients with learning disabilities were managed solely by consultants in this speciality. This extended to the management of physical conditions. So for example, a healthy adult patient, with problems of epilepsy would be managed by a neurologist. This would not be the case for a patient with a learning disability. It could therefore be argued that these patients did not receive optimal care.

The parallels to be drawn from this, and lessons to be learnt, must be that rigid age criteria are generally inappropriate and the patient should be catered for in

an environment which meets their needs. This must include both physical and psychosocial needs as well as being best able to meet the needs the individual has as a patient.

3.1.6 Conclusions

Adolescence cannot effectively be described solely by chronological age. It must take account of stages of development. However teenage units probably need to have broad, but flexible, age limits which probably start no earlier than 10 years, but are very dependent on the maturity of the child. At the older end, again, a degree of flexibility needs to be exercised. For some 20-24 year old with recurrence, it might indeed be appropriate for these to be managed by the adolescent team, but for others it may not be appropriate. Individual judgements by the clinicians responsible for the care of these patients will need to be exercised. For the purposes of this study, data will be examined in relation to cancer in three distinct age bands 10 -14, 15 -19, 20 -24. Some data will also be presented by single years, but by and large complex data analysis is not practical at this level because of relatively small numbers.

3.2 The health and health needs of adolescents and young adults

3.2.1 Causes of Death in Adolescents

Adolescence is characterised by good health. In 1993 there were 3985 deaths in the age range 10 –24 in England and Wales. Table 3.2.1 shows the major causes of death in this age group (in five-year age bands). This shows that when both sexes are taken together, the overwhelming cause of death in this age group is from injury and poisoning. Furthermore, it should be noted that there are around five times as many deaths in males compared to females in the 20-24 year age band and three and twice as many in the 15-19 and 10-14 respectively. This excess is largely accounted for by injuries and poisoning, although when figures for these causes are removed, there is still an excess of death in males compared to females of between 1.23 and 1.63 to one. (table 3.2.2)

Table 3.2.1 Numbers of deaths from all causes in 10-24 year olds - England and Wales 1993

Cause of death (ICD 9)	Sex	Age range 10-14	15-19	20-24
I Infections	M	16	22	19
(001-139)	F	12	18	19
II Neoplasms	M	61	89	139
(140-239)	F	52	48	99
III Endocrine, nutritional and metabolic	M	13	20	30
(240-279)	F	11	29	22
IV Blood and blood forming organs	M	6	5	9
(280-289)	F	6	4	3
V Mental Disorders	M	6	33	46
(290-319)	F	1	6	12
VI Nervous system and sense organs	M	48	81	87
(320-389)	F	26	44	30
VII Circulatory system	M	15	41	84
(390-459)	F	17	21	58
VIII Respiratory system	M	17	41	36
(460-519)	F	28	18	32
IX Digestive system	M	4	12	14
(520-579)	F	2	4	15
X Genito-urinary system	M	1	5	6
(580-629)	F	2	0	7
XI Complication of pregnancy	M			
(630-676)	F	0	1	1
XII Skin and subcutaneous tissue	M	1	0	6
(680-709)	F	0	2	1
XIII Musculoskeletal system	M	1	3	3
(710-739)	F	2	5	3
XIV Congenital abnormalities	M	23	21	25
(740-759)	F	20	19	25
XV Conditions in antenatal period	M	0	0	1
(760-779)	F	0	0	0
XVI Signs, symptoms and ill defined	M	2	2	11
(780-799)	F	1	4	3
EXVII External causes of injury and poisoning	M	121	527	1058
(E800-E999)	F	66	159	227
All causes	M	333	902	1569
	F	237	382	562

Source: Office of National Statistics. DVS3.L 1993

Table 3.2.2 Numbers of deaths from all causes in 10 - 24 year olds demonstrating the effect of removing deaths from injuries and poisoning

Cause of death (ICD 9)		Age range		
	Sex	**10-14**	**15-19**	**20-24**
All causes excluding injuries and poisoning	M	212	375	511
	F	171	223	335
Ratio of Males to Females*		1.23	1.68	1.53

*Unadjusted for population at risk
Source: Office of National Statistics. DVS3.L 1993

A further breakdown of the nature of the injury classification is shown in tables 3.2.3 which illustrates that most of the deaths in these age groups are taking place amongst young men from motor vehicle accidents. However, the level of suicides in young men between 20 and 24 is the greatest single cause of death in the 20 - 24 year old category.

Table 3.2.3 Numbers of deaths from External Causes in 10 -24 year olds - England and Wales 1993

		Age range		
External Cause (ICD 9)	Sex	10-14	15-19	20-24
Motor vehicle accidents	M	55	256	355
(E819-819)	F	43	86	74
Accidental poisoning	M	2	43	84
(E850-869)	F	5	7	27
Accidental falls	M	4	19	26
(E880-888)	F	1	4	3
Accidental cause by fire	M	33	46	84
(E890-929-173)	F	7	5	9
Suicide and self inflicted	M	19	130	444
(E950-959)	F	6	33	90
Homicide	M	4	22	49
(E960-969)	F	3	21	21
Others	M	4	11	16
Others	F	1	3	3
Total	M	121	527	1058
(E800-999)	F	66	159	227

Source: Office of National Statistics. DVS3.L 1993

The number of suicides in young men is a well-recognised phenomenon which successive governments have attempted to address through National Strategies. (20) (21)

3.2.2 Deaths from cancer in adolescents

Data have been obtained on deaths from neoplasms for the age group 10-24 from ONS. Data were only made available for the first time in 1993 in 5-year age bands and therefore these data has been shown.

Table 3.2.4 Numbers of deaths from neoplasms in 10-24 year olds - England and Wales 1992

Cancer site (ICD 9)	Sex	Age range 10-14	15-19	20-24
Lip, oral cavity and pharynx	M	0	1	2
(140-149)	F	1	2	0
Digestive Organs	M	3	1	8
(150-159)	F	0	3	10
Respiratory Tract	M	0	1	3
(160-165)	F	0	0	1
Bone	M	7	7	10
(170)	F	9	18	10
Skin	M	0	5	5
(172-173)	F	1	2	7
Female Breast (174)	F	0	0	3
GU Organs	M	2	1	11
(179-189)	F	1	0	13
Cervix (180)	F	0	0	2
Testis (186)	M	1	1	8
Brain	M	17	19	20
(191)	F	8	5	12
Lymphatic and Haemopoietic	M	28	48	61
(200-208)	F	10	24	42
Lymphoid leukaemia	M	14	27	24
(204)	F	4	10	12
Myeloid leukaemia	M	4	9	9
(205)	F	5	6	13
Benign and other unspecified	M	0	4	1
(210-229)	F	0	1	2
Total	M	70	95	141
	F	36	62	116

Source: Office of Population Censuses and Surveys (22)

Table 3.2.4 shows the number of deaths from neoplasms in each age group in England and Wales in 1992. The data which are presented later in this study relate to incidence of disease, rather than death. This table illustrates the mortality from cancer in these age groups.

The table illustrates that the predominance of deaths is from lymphatic and haemopoietic causes, a further breakdown of these data can be seen in table 3.2.5. This table illustrates the larger number of deaths from Hodgkin's disease in older age groups (reflecting the incidence) together with a greater number of deaths from myeloid leukaemia as the teenagers and young adults get older.

Table 3.2.5 Numbers of deaths from neoplasms of the lymphatic and haematopoietic tissues in 10 -24 year old - England and Wales 1992

Cancer site (ICD 9)		**Age range**		
	Sex	10-14	15-19	20-24
Lymphosarcoma and	M	1	1	2
Reticulosarcoma (200)	F	0	1	0
Hodgkin's Disease	M	0	5	13
(201)	F	0	3	9
Non Hodgkin's Lymphoma	M	7	6	12
(202)	F	1	3	7
Myeloid leukaemia	M	4	9	9
(205)	F	5	6	13
Lymphoid Leukaemia	M	14	27	24
(204-)	F	4	10	12
Total (200-208)	M	28	48	61
	F	10	24	42

Source: Office of Population Censuses and Surveys (22)

3.2.3 Incidence of cancer in adolescents

Of course, the burden of disease cannot be solely represented by examining mortality statistics. As will be discussed in chapter 5, cancer is unique in the UK in having a well established registration system. It is therefore possible in cancer to examine well established data which do not exist in other areas of health and disease

Table 3.2.6 Registrations of newly diagnosed cases of cancer 1992 - England and Wales

Cancer site (ICD 9)	Sex	Age range 10-14	15-19	20-24
Lip, oral cavity and pharynx	M	4	4	7
(140-149)	F	3	9	7
Digestive Organs	M	1	4	11
(150 - 154, 157)	F	2	4	9
Respiratory Tract	M	1	3	1
(161,162)	F	0	2	4
Bone	M	14	29	19
(170)	F	15	16	14
Melanoma of Skin	M	2	5	27
(172)	F	5	18	71
Female Breast (174)	F	1	6	29
GU Organs	M	3	34	155
(180-189)	F	4	19	82
Cervix (180)	F	0	3	34
Ovary (183)	F	1	11	35
Testis (186)	M	2	30	144
Brain	M	44	40	45
(191)	F	34	23	24
Non Hodgkin's Lymphoma	M	22	30	35
(200 & 202)	F	11	19	23
Hodgkin's Disease	M	24	43	86
(201)	F	12	47	78
Leukaemias	M	40	49	60
(204 - 208)	F	21	38	36
Lymphoid leukaemia	M	24	27	19
(204)	F	11	15	9
Myeloid Leukaemia	M	16	19	40
(205)	F	9	21	24
Carcinoma in situ cervix (233.1)	F	0	291	2728
Total (excluding 173 non melanoma skin cancer)	M	186	277	503
Total (excluding 173 non melanoma skin cancer and in situ carcinoma of the cervix)	F	120	243	457

Source: Office of National Statistics. (23)

This table illustrates the importance of tumours of the testis in men, and of brain tumours. It also shows the importance of malignant melanoma in women aged 20-24. The following table combines males and females and shows a percentage for each malignancy.

Table 3.2.7 Registrations of newly diagnosed cases of cancer 1992 - England and Wales showing the burden of each disease

Cancer site (ICD 9)	Number				%			
Age band	10-14	15-19	20-24	10-24	10-14	15-19	20-24	10-24
Lip, oral cavity and pharynx (140-149)	7	13	14	34	2.29	2.50	1.46	1.90
Digestive Organs (150 - 154, 157)	3	8	20	31	0.98	1.54	2.08	1.74
Respiratory Tract 162	1	5	5	11	0.33	0.96	0.52	0.62
Bone (170)	29	45	33	107	9.48	8.65	3.44	5.99
Melanoma of Skin (172)	7	23	98	128	2.29	4.42	10.21	7.17
Female Breast (174)	1	6	29	36	0.33	1.15	3.02	2.02
GU Organs (180-189)	7	53	237	297	2.29	10.19	24.69	16.63
Cervix (180)	0	3	34	37	0.00	0.58	3.54	2.07
Ovary (183)	1	11	35	47	0.33	2.12	3.65	2.63
Testis (186)	2	30	144	176	0.65	5.77	15.00	9.85
Brain (191)	78	63	69	210	25.49	12.12	7.19	11.76
Non Hodgkin's Lymphoma (220 & 202)	33	49	58	140	10.78	9.42	6.04	7.84
Hodgkin's Disease (201)	36	90	164	290	11.76	17.31	17.08	16.24
Leukaemias (204-208)	61	87	96	244	19.93	16.73	10.00	13.66
Lymphoid leukaemia (204)	35	42	28	105	11.44	8.08	2.92	5.88
Myeloid Leukaemia (205)	25	40	64	129	8.17	7.69	6.67	7.22
Total	306	520	960	1786	100.00	100.00	100.00	100.00

Much of the routinely available data is inadequate to provide a comprehensive picture of adolescent cancer both regionally, nationally and internationally. As Viner (3) pointed out as far as the UK is concerned, the standard approach to presenting data divides adolescents as the usual groups are 0-14 and 15-44. This also applies to much internationally compiled data, where again standard age breakdowns covering these areas of interest are 0-14 and 15-44 (24) (25) However, some data are presented below (tables 3.2.8 – 3.2.9) from published sources, but it is clear that illustrates the difficulty of examining cancer in this age group because of the inconsistencies in describing data in young people and its completeness. In addition discussion on the appropriateness of the classification used is discussed further in chapter 6. These tables of limited data, suggest that the incidence and survival in the Northern and Yorkshire

region is broadly similar to England and the registries involved in the SEER programme in the United States. Table 3.2.10 shows the incidence of selected cancers from selected registers in comparison to the incidence reported by the Yorkshire Cancer Registry as published in Cancer in Five Continents (26) (the Northern Registry did not submit data in this period). These data would suggest that the incidence of cancer in Yorkshire is well within the range experienced elsewhere in the world.

Table 3.2.8 Incidence of selected cancers per 100,000 in young people from published sources

	Geography	Period	Sex	Age band		
				10-14	15-19	20-24
All cancers	SEER[3]	1986-1995	M	-	20.4	-
			F	-	19.9	-
	England[4]	1995	M	12.20	16.60	26.40
			F	9.80	13.60	25.90
	Yorkshire[5]	1989-1993	M	11.70	15.60	22.10
			F	8.60	13.00	21.90
	Northern[4]	1989-1993	M	10.40	17.50	21.70
			F	7.90	9.60	19.20
Leukaemias	SEER	1986-1995	M	-	2.6	-
			F	-	1.6	-
	England	1995	M	3.70	3.10	1.90
			F	1.60	1.30	1.50
	Yorkshire	1989-1993	M	2.70	1.90	1.20
			F	2.70	1.70	1.60
	Northern	1989-1993	M	2.10	3.10	2.00
			F	2.00	2.20	1.70
NHL	SEER	1986-1995	M	-	1.9	-
			F	-	1.1	-
	England	1995	M	1.60	1.60	2.50
			F	0.50	0.70	1.50
	Yorkshire	1989-1993	M	1.00	1.80	1.20
			F	0.40	0.50	1.00
	Northern	1989-1993	M	0.90	1.00	1.50
			F	0.50	0.20	1.10
Hodgkins	SEER	1986-1995	M	-	2.9	-
			F	-	3.6	-
	England	1995	M			
			F			
	Yorkshire	1989-1993	M	1.50	3.00	4.00
			F	0.50	3.90	3.80
	Northern	1989-1993	M	1.30	4.60	4.20
			F	0.20	1.50	3.70
CNS tumours	SEER	1986-1995	M	-	2.3	-
			F	-	1.7	-
	England	1995	M	1.70	1.20	2.10
			F	2.00	1.40	0.90
	Yorkshire	1989-1993	M	2.60	1.80	1.60
			F	1.60	1.30	1.00
	Northern	1989-1993	M	1.90	2.10	2.40
			F	1.40	1.10	0.70

[3] SEER http://www-seer.ims.nci.nih.gov/Publications/ (see Annex 2 for explanation of SEER)

[4] Office for National Statistics. Statbase. Http:/www.statistics.gov.uk/statbase

[5] Northern and Yorkshire Cancer Registry. Quickdata. Version 2 1999

Table 3.2.9 Survival from selected causes from published data sources

	Geography	Period	Sex	Age band		
				10-14	15-19	20-24
All cancers	SEER[2]	1986-1995	Both	-	77	-
	England[3]	1995	M			
			F			
	Yorkshire[4]	1989-1993	M	67.8	73.5	75.9
			F	66.0	80.6	70.4
	Northern[4]	1989-1993	M	69.5	68.2	73.4
			F	58.9	66.0	75.6
Leukaemias	SEER	1986-1995	Both	-	46.5	-
	England	1995	M			
			F			
	Yorkshire	1989-1993	M	*	*	*
			F	*	*	*
	Northern	1989-1993	M	*	*	*
			F	*	*	*
NHL	SEER	1986-1995	Both	-	69	-
	England	1995	M			
			F			
	Yorkshire	1989-1993	M	*	*	*
			F	*	*	*
	Northern	1989-1993	M	*	*	*
			F	*	*	*
Hodgkins	SEER	1986-1995	Both	-	90	-
	England	1995	M			
			F			
	Yorkshire	1989-1993	M	*	*	93.7
			F	*	87.1	77.9
	Northern	1989-1993	M	*	91.3	83.0
			F	*	*	90.1
CNS	SEER	1986-1995	Both	-	75	-
	England	1995	M			
			F			
	Yorkshire	1989-1993	M	*	*	*
			F	*	*	*
	Northern	1989-1993	M	*	*	*
			F	*	*	*

- less than 20 observations

Table 3.2.10 Incidence rates for selected cancers from published cancer registry data world-wide [6]

Australia - New South Wales						
1988-1992	10-14		15-19		20-24	
Disease	Males	females	males	females	Males	females
Acute lymphoid lymphoma	2.0	2.2	2.2	0.9	0.9	0.6
Hodgkin's Disease	1.1	0.6	2.6	1.7	2.9	3.0
Non Hodgkin's Lymphoma	1.5	0.3	1.6	0.9	2.3	1.1
CNS Tumours	2.6	2.9	2.3	2.4	2.8	2.0
Bone tumours	1.0	0.7	2.4	1.1	0.6	0.6
All malignancies	11.9	10.6	24.4	18.6	34.8	34.4

Canada - British Columbia						
1988-1992	10-14		15-19		20-24	
Disease	Males	females	males	females	Males	females
Acute lymphoid lymphoma	2.8	1.7	1.1	0.9	1.0	0.7
Hodgkin's Disease	2.0	-	3.8	0.2	2.6	-
Non Hodgkin's Lymphoma	0.7	0.8	1.1	1.3	2.0	2.2
CNS Tumours	3.1	2.3	1.6	1.5	2.3	2.0
Bone tumours	1.1	1.9	1.1	1.3	0.8	0.3
All malignancies	12.3	11.4	15.8	18.7	24.8	28.7

Switzerland - (Geneva)						
1988-1992	10-14		15-19		20-24	
Disease	Males	females	males	females	Males	females
Acute lymphoid lymphoma	4.0	-	5.2	-	1.5	-
Hodgkin's Disease	-	-	3.5	3.5	1.5	4.1
Non Hodgkin's Lymphoma	2.0	4.2	5.2	-	10.3	1.4
CNS Tumours	-	-	1.7	-	2.9	1.4
Bone tumours	-	-	3.5	-	4.4	1.4
All malignancies	9.9	8.3	28.0	15.9	42.6	27.6

Yorkshire						
1987-1992	10-14		15-19		20-24	
Disease	Males	females	males	females	Males	females
Acute lymphoid lymphoma	1.6	1.3	1.4	0.8	0.3	0.1
Hodgkin's Disease	1.4	0.6	2.7	3.9	3.8	4.0
Non Hodgkin's Lymphoma	2.1	1.1	2.2	0.3	1.2	1.0
CNS Tumours	2.1	1.9	1.9	1.1	1.5	1.0
Bone tumours	1.2	1.1	0.9	1.6	0.7	0.4
All malignancies	11.0	8.5	15.3	13.3	19.6	20.6

Source: Cancer Incidence in Five Continents Vol. VII. Eds. D.M.Parkin. S.L.Whelan, J.Ferlay, C. Raymond, J.Young. IARC Scientific Publication 143. Lyon 1997 (26)

Finland						
1987-1992	10-14		15-19		20-24	
Disease	Males	females	males	females	Males	females
Acute lymphoid lymphoma	2.2	1.6	2.1	1.1	0.8	0.4
Hodgkin's Disease	0.9	1.4	2.3	3.5	3.2	1.9
Non Hodgkin's Lymphoma	0.8	0.8	2.1	0.4	1.9	1.5
CNS Tumours	3.6	3.0	2.6	2.6	3.3	3.3
Bone tumours	1.1	0.6	1.6	0.9	0.5	1.3
All malignancies	11.6	12.3	18.4	18.4	23.2	27.9

UK Scotland						
1988-1992	10-14		15-19		20-24	
Disease	Males	females	males	females	males	females
Acute lymphoid lymphoma	1.7	1.6	2.5	1.1	0.5	0.2
Hodgkin's Disease	1.4	1.8	2.1	3.2	5.1	3.5
Non Hodgkin's Lymphoma	1.7	0.4	1.2	0.8	1.8	1.9
CNS Tumours	3.1	2.8	2.4	1.7	2.3	1.1
Bone tumours	1.4	0.8	1.9	0.9	0.7	0.4
All malignancies	11.5	10.9	18.2	15.9	28.0	22.2

4 Literature review

4.1 Sources and Methods

4.1.1 Medline

There is an extensive literature on cancer in adolescents. The American National Library of Medicine makes available an on-line Medline service. (27) The NLM's search service has access to nine million citations in Medline and other related databases. Entering the terms 'adolescent' and 'cancer' revealed 116,868 references - 42,148 related to the previous ten years. In the past year alone 3,930 articles met the stated criteria. In order to restrict the number of articles to a manageable level the search was repeated on titles and text words (tw - neoplasms, cancer, adolescent). At this stage searches were also restricted to articles published in English. No specific quality criteria were used in the initial search.

Table 4.1 Results of Medline search

Year	Neoplasms	Adolescent (tw)	Number of Articles Adolescent (tw) and Neoplasms
1999 - 1996	16171	4924	49
1995 - 1991	20367	5183	48
1990 - 1985	21640	4901	55
1984 - 1976	25451	3933	22
1975 - 1966	18219	1648	3

Abstracts for all the identified articles were obtained and scanned for relevance. A significant number of articles related to the adjustment of children and adolescents to parental cancer. As this is not the subject of this investigation these articles were excluded. For the purposes of this investigation the literature was classified into following groups.

- Epidemiology of cancer in adolescents
- Specific cancers of adolescents
- The psychological impact of cancer in adolescents
- The evidence for the creation of centralised services for patients with cancer

4.1.2 Nursing Literature (CINAHL)

The nursing literature of 1982 - December 1999 was searched using textword adolescent and neoplasm. The results were:

Table 4.2 Results of Nursing Literature Search

Adolescent	Neoplasm	Adolescent and Neoplasms
2787	4112	40

4.1.3 Review of Psychology Literature

Psychology literature is held on a specialist database called Psyclit. In the same way as previous searches were carried out, the terms adolescent and cancer or neoplasm were used. The database was searched between 1991 and September 1998. The results of the search were as shown in the table below:

Table 4.3 Results of psychological literature search

Adolescent	Neoplasm	Adolescent and Neoplasms
5971	2814	32

Thirty-two articles were identified in the time period 1991 to 1998 (September).

4.1.4 Review of Sociology Literature

Sociofile is a tool for accessing the literature in applied sociology, social and policy science. The database contains abstracts from 2300 journals published since 1974. Twenty three articles were identified using the search terms cancer and adolescent (or young adults) since 1990.

Some overlap of articles was noted, this was particularly evident with psyclit and medline.

4.2 Epidemiology of cancer in adolescents

A considerable number of studies exist for cancer in children (aged 0 - 14 years) (28) (29) (30). Fewer studies present data for children and adolescents above 14 years of age. A study published by Fritschi (31), which looked at the incidence of cancer amongst New South Wales adolescents concentrated principally on the appropriate classification scheme in a study of adolescents aged 10 - 19 with cancer between 1972 and 1991 in New South Wales. 2,620 cases of cancer were diagnosed, the average (crude) incidence rate for all cancers combined was 158 and 140 per million in males and females, respectively. The authors concluded that the childhood classification scheme is an appropriate scheme to describe cancer incidence in adolescent age groups but perhaps requires minor modifications. A striking finding of the New South

Wales study was the high level of incidence of malignant melanoma. Australian adults have the highest incidence rates of melanoma in the world (32) and the rate in New South Wales' children is also much higher than in any other country (33)

A population based study was carried out on 3,988 tumours in teenagers (aged 10 - 19) in Denmark, and published in 1993 (34). The average incidence rates for all histological types were found to be 136 per million for boys and 108 per million for girls. Like most studies, an overall excess of cancer in boys was mainly due to the frequency of leukaemias, malignant lymphomas, carcinomas and germ cell tumours. This study suggested that, with the exception of increasing trends in malignant lymphoma and in non-seminoma germ cell tumours amongst boys aged 15 - 19, the rates have remained largely unchanged. The authors draw the conclusion from their study that environmental factors associated with modern society therefore play a small role in the causation of cancer among teenagers.

Broadly similar (standardised incidence) findings were reported in a study published by Van Hoff in 1988 (35) of the trends in the incidence of childhood and adolescent cancer in Connecticut between 1935 and 1979. However, this study looked at the incidence of specific cancers in children in 5-year age bands between 0 and 19, and found significant increases in incidence over time in Hodgkin's disease in males aged 15-19 and in females aged 10-19.

Pollán et al. (36) published a report on the trends in mortality in the under 20 year olds in the population of Spain between 1956 and 1990. They looked at

the mortality from seven sites and reported that overall mortality had declined over this period. This decline had begun to occur at the beginning of the 1970s. The decline was not apparent in malignant renal tumours in males and malignant bone tumours and non-Hodgkin's lymphoma in both sexes. As the incidence of malignancy in this age group was reported as not changing, the authors concluded that the decline (where it could be demonstrated) was due to better treatment and improved facilities.

In 1992, Adami et al (37) reported trends in survival in adolescent cancer in Sweden between 1960 and 1984, however, this study did not report incidence (standardised or crude) data for the respective age bands studied.

In 1996 Weiss et al (38) published a study of 788 malignancies in Texas residents under the age of 20 and found that the incidence of cancer in Hispanics was significantly lower than that seen in other racial and ethnic groups. In particular, they found a lower incidence of total cancers, non-Hodgkins lymphoma, lymphoma, neuroblastoma and CNS neoplasms in Hispanics compared to other young Texans. However the overall incidence of leukaemia and acute non-lymphocytic leukaemia in particular, was highest among the Hispanics.

In the Northern and Yorkshire Region there are significant ethnic minorities from South Asia. 1979 Children (aged up to 14 years) with cancer were studied between 1974 and 1995. It is known that cancer incidence in the UK does vary by ethnic origin, with a notable excess of lymphomas in children of Asian ethnic origin. (39). McKinney et al found that survival did not differ in any ethnic group.

Risk of death was higher for children in most deprived areas though these differences did not reach statistical significance (40).

Unlike in children where leukaemias are the commonest form of cancer, lymphomas are more common in adolescents. Leukaemia and brain tumours are also very common. When looking at the differences in distribution between the sexes in a study carried out in Canada, it is notable that there were around a forty percent excess of cancer reported in males (41), with a 70% excess in non Hodgkin's lymphoma, whereas there was almost no difference between the sexes in the incidence of Hodgkin's disease (though this may be partly explained by the fact that the female group was slightly older than the male group). Similarly it has been reported that there is a three to four fold excess of thyroid cancer in females and a fifty percent excess in malignant melanoma. Similar patterns were seen in the SEER programme in the United States (where only the white population was used for comparative purposes), but an even greater excess of non-Hodgkin's disease was seen there.

In childhood, leukaemias account for almost a third of cancers, whereas in adolescents this falls to about one seventh, with the lymphomas becoming much more prominent (accounting for one in four cancers in the 10-19-age range). Embryonal tumours such as Wilm's tumour (nephroblastoma), retinoblastoma and hepatoblastoma are hardly ever seen in the older age groups.

4.3 Specific cancers in adolescents and risk factors

In this section, cancers that affect young people will be considered individually.

4.3.1 Hydatidiform Moles

A hydatidiform mole is a rare mass or growth that may form inside the uterus at the beginning of a pregnancy. Only 20% of hydatidiform moles care malignant.

Hydatidiform moles arise from foetal tissue and, therefore can only occur in conjunction with the early stages of pregnancy. The mass is usually placental material that grows uncontrolled. Frequently there is no foetus at all. The cause of this developmental disorder is not completely understood. Potential causes may include defects of the ovum (egg), abnormalities within the uterus, and/or nutritional deficiencies. The incidence in the U.S. is 1 out of 1500 pregnancies; however, it occurs in up to 1 out of 125 pregnancies in Mexico and some Asian countries. Women under 20 or over 40 years old have an increased incidence. Risk factors include low socio-economic status and diets low in protein, folic acid and carotene. (42) (43)

An hydatidiform mole is treated by therapeutic abortion, if spontaneous abortion does not occur.

The prognosis is mainly good. More than 80% of hydatidiform moles are benign and the outcome after treatment is usually excellent. Close follow-up is essential. Highly effective means of contraception are recommended to avoid pregnancy for at least 1 year.

In 10 to 15% of cases, hydatidiform moles may develop into invasive moles. Invasive moles, however, may intrude so far into the uterine wall that haemorrhage or other complications develop.

In 2 to 3% of cases, hydatidiform moles may develop into choriocarcinoma which is malignant. Despite these factors, the rate of cure is high. Over 90% of women with malignant, non-spreading (non-metastatic) disease are able to preserve reproductive abilities. In those with metastatic disease, remission remains at 75 to 85%.

4.3.2 Cervical Cancer and CIN III

Risk factors for cervical cancer are shown in the box below.

Box 4.1 Risk factors for cervical cancer (44)

- Early first intercourse (coitus below 17 doubles risk) (45)
- Women with multiple sexual partners (45)
- Promiscuous male partners (more than 15 partners - 8 times risk) (45)
- Smoking (doubles risk) (46)
- cervical trauma during childbirth (46)
- Sexually transmitted viral infection (especially HPV16 - present in 93% of cervical cancer (45)
- Genetic susceptibility (a variation in p53 tumour suppresser gene may increase risk 7 times (47)

In numeric terms the numbers of CIN III form the largest number of new cancers in the 10 -24 year old age group compared with any other site. One of the principal differences between the Yorkshire Cancer Registry and the Northern Children's' Tumour Registry was found to be that the Yorkshire Registry recorded CIN IIIs. CIN IIIs are carcinoma in-situ of cervix. There is evidence to show that there has been a real increase in incidence of these cancers, particularly in the younger age groups.

Doll (48) reports a 10% increase in cervical cancer in the 20 - 24-year-old age group. It is now widely accepted that that this is due to increased infection with carcinogenic types of human papilloma virus (49) (50) (51). One of the

dilemmas facing the gynaecologists who are responsible for managing young women with cervical abnormalities is the natural history of cervical displasia and CIN I. To what extent these conditions progress to invasive cervical carcinoma is unclear. In this study CIN III will not be considered, but this does not mean that the discovery of this potentially serious abnormality in young women does not have a profound effect on the well being of the patient concerned. There are significant issues about how this condition should be managed from a psychological perspective in young women and there are implications for health promotion and the screening services (including those in primary care) in providing full information for young women being screened.

4.3.3 Leukaemias

Most of the published material on leukaemias relates to childhood leukaemia and to a lesser extent adult leukaemia. As Cartwright suggests (52) there are virtually no epidemiological studies which target adolescents. The aetiology of cancer in adolescents cannot be assumed to be similar to that of children. Nationally between 1983 and 1987 leukaemias were reported to constitute around one fifth of new cases of malignancy in males in the 10-19 year old age group and slightly less in females (41)

It is thought that ALL (acute lymphoblastic leukaemia) in adolescents is likely to have a similar epidemiological picture to that in children (52). Table 4.4. shows the distribution of AML, CML and ALL in 15-24 year olds. This table emphasises the excess of ALL, especially seen in boys between the ages of 15 and 19 years of age.

Table 4.4 Incidence (per 100,000 per year) of selected haematological malignancies

Disease		Age group 15-19	20-24
Acute myeloid leukaemia	M	0.5	1.0
	F	0.7	0.6
Chronic myeloid leukaemia	M	0.2	0.1
	F	0.2	0.1
Acute lymphoblastic leukaemia	M	1.7	0.7
	F	0.8	0.3

Source: Cartwright (52)

Risk factors are virtually unknown with some studies now being undertaken. Little is known about AML (acute myeloid leukaemia) in adolescents.

4.3.4 Non Hodgkins Lymphoma (NHL)

Cartwright (52) suggests that NHL in adolescents is likely to be similar in its aetiology to that in children with the exception of the viral causes. There are some inherited impaired immune system conditions which give rise to NHL in adolescence (53). There are links between NHL and certain other chronic diseases for example glomerulonephritis. NHL is increasing in incidence in adults in the US and many other countries, but there is no evidence that this increase extends to adolescents.(54) (55)

4.3.5 Hodgkin's Disease

This disease appears to be increasing in incidence, there is good evidence from North America that there has been a marked increase in incidence since the early 1970s which was not due to better diagnostic capabilities (56).

Hodgkin's disease peaks in incidence at in the early 20s and 30s, then in the early part of the peak, there is no difference between the sexes, but at other

ages there is a male excess. A number of studies have suggested that there is an excess of this disease in 'upper social' classes, but this may be more due to where they live than their socioeconomic status (57).

Gutensohn and Cole (58) have suggested that a number of features of Hodgkin's disease suggest that it has an infectious aetiology. They suggest that Hodgkin's disease may be a late manifestation of a common infection with the probability of disease increasing as age at infection is delayed. This hypothesis is supported by the reports that the risk of Hodgkin's disease is increased in those who had a low frequency of childhood infectious disease. In a study of 225 cases and 447 controls, they showed that the risk of disease decreased with five or more siblings, living in multiple family homes. Cases had fewer playmates and better educated mothers than the controls. They concluded that this study added weight to their earlier hypothesis that risk of Hodgkin's disease is associated with a decrease or delay in exposure to infections of childhood (59).

Clustering is a feature of Hodgkin's disease, most especially in isolated rural populations. In a study by Alexander almost 1 in 3 cases could be spatially linked to another (60).

Familial studies suggest that Hodgkin's disease has a genetic basis. It is thought that the disease may occur more commonly in genetically susceptible individuals with perhaps some infective agent being involved in the late stage of the pathogenesis. Viruses that have been suggested include the Epstein Barr virus (61), although the extent to which this virus is involved in young people

with Hodgkin's disease is thought to be small (62) and the herpes virus (HHV6) (63). There have also been some suggestions that Hodgkin's disease is linked to skin conditions (64) and inherited conditions (53) giving rise to immune deficiency. Other associations with tonsillectomy and appendicectomy appear to have now been refuted (65).

4.3.6 Brain and CNS Tumours

About half CNS tumours in adolescents and children occur in the posterior fossa. Boyle concluded that despite the many suggested factors proposed for cancer of the brain and the CNS, there is little which can be suggested that may increase the prospects of preventing brain and CNS tumours in adolescents at the present time. (41)

4.3.7 Bone Cancer

Approximately 10% of all malignant neoplasms in children and adolescents are due to bone cancer (66). 95% of these are either osteo-sarcoma or Ewing's sarcoma. Osteo-sarcomas are twice as common as Ewing's sarcoma. Approximately 60% of patients with this tumour are affected during the second decade of life, with a predominance of males. There is a suggestion that this neoplasm is related to rapid bone growth (67). There is a suggestion that osteo-sarcoma may be genetically pre-determined. The main evidence for this comes from observations of excess osteosarcoma as a second malignancy in-patients with hereditary retinoblastoma (68).

Ewing's-sarcoma occurs mainly between the ages of 5 and 30, with a peak incidence of between 10 and 15 years. More boys than girls are affected, and this tumour is rare in black and Chinese populations.

4.3.8 Testicular cancer

Cancer of the testis has been increasing since the 1930s in this country. In Scandinavia where the rates are double that in the UK the increase is most marked in the 15-19 age group. In contrast to the increase in incidence is the decline in mortality, which is associated with effective treatment. The reasons for the increase in incidence are unclear, and cannot be satisfactorily accounted for by factors which are known to cause an increase (earlier sexual maturity and undescended testis). (69) (70)

4.3.9 Skin Cancers

Significant increases have occurred in melanoma and non-melanoma of the skin (48). There is a striking increase in melanoma and non-melanoma skin cancer. In the United States, Kaposi's-sarcoma associated with AIDS has been an important factor in the increase of non-melanoma skin cancer in young men (71). However, it is unlikely that this condition has played a significant part in the United Kingdom. The only other risk factor known to cause skin cancer is exposure to ultra-violet radiation (72), but it has been questioned whether such an increase in exposure since the 1960s can account for a 56% and 28% increase in male and female melanomas, and the 22% and 29% increase in non-melanoma skin cancer, respectively (73).

4.3.10 Drugs as causative factors

Two instances of drugs causing cancer in adolescents have been described. Cyclophosphamide is associated with carcinoma of the bladder (74) and diethylstiboestrol treatment of pregnant mothers has led to clear cell carcinoma of the vagina in their daughters (75).

4.4 The psychological and sociological impacts of cancer in adolescents

4.4.1 The psychological literature

Stevens and Dunsmore provide a useful overview of the issues facing the adolescent with cancer (76). Their review provides an analysis of the situation of adolescents who are living with life-threatening illnesses, and provides strong evidence for the need to handle adolescents with cancer differently to adults or children. For example, they describe some of the features of how adolescents react to a crisis and point out that "their response is typically that they want to be loved and supported but not wrapped in cotton wool." They point out that rather than confide in parents , they may prefer to confide in their peer group, particularly with peers who are in a similar situation. In addition to coping with what is already a stressful part of life, adolescents with cancer are having to cope with the stresses associated with the illness, its treatment and side effects of therapy. They point out the resilience and soundness of mind of the affected young people, and emphasise that most young people want to be actively involved with understanding their illness and take an active part in the treatment decisions associated with it. The authors draw interesting distinctions between the needs of adolescents at various ages and group these into early, middle

and late adolescence. Thus, for example they describe the major concerns of early adolescents as those which revolve around body image and mobility. Mid adolescents are concerned about how their illness will affect their ability to form relationships, particularly with the opposite sex, and late adolescents (17 – 24) with forming permanent relationships and their careers.

Bradlyn (77) points out the difficulty of assessing quality of life in special populations, especially children and adolescents. He points out that little research has been done in these groups, and suggests that there are a number of conceptual and technical difficulties related to the assessment of the quality of life in children and adolescents. He points out that a wide range of differences need to be taken into account in studies which cover ages which encompass infancy to adulthood. He also pointed out the importance of assessing secular changes as children move from one developmental stage to the next. He also highlights the difficulties of using proxy informants (e.g. parents in children and adolescents). In a study of quality of life in AIDS, Testa and Simonson concluded that it was necessary to use three different quality of life instruments corresponding to developmental age (6 months to 4 years, 5 to 11 years and 12 to 20 years). Furthermore, for children under the age of 12, the respondent was the child's carer rather than the child. (78)

Eiser and Havermans, (79) on the other hand looked at the mothers and fathers from 245 families with a child (ages 4-14 years) with a severe life limiting condition, including leukaemia. Their study particularly examined coping patterns. These varied according to age and gender of the child, and, more significantly, in relation to the disease and length time to since the diagnosis was made. Mothers reported that social support and information was felt to be

less helpful the longer the time since diagnosis, and this was particularly the case with leukaemia and epilepsy. On the other hand the fathers who perceived more difficulties found autonomy more helpful and medical care less helpful compared with fathers who perceived fewer difficulties. In a later study Eiser (80) also considered the long term effects of childhood cancer, and suggested that for these children, consideration should be given to the long term care in order to (a) establish more accurately the incidence of social and psychological late effects and (b) offer advice to the individual about the possible long-term effects of cancer treatment on future health, social and employment prospects.

The follow up of children with cancer is one possible role for an adolescent cancer unit and is a distinct function which does not appear to have received much attention in either the literature or in the provision of services.

Alice Friedman (81) undertook a study on the psychological functioning of children with cancer. She identified the most critical issues relevant to children diagnosed under fifteen years, and also illustrated the range of demands which confront children and their families after receiving a diagnosis of cancer. She also described how behavioural research has contributed to the overall care and adjustment.

Glazer (82) describes the psychiatric aspects of cancer in childhood and adolescence from the first time from which the child is diagnosed through treatment and other longer-term situations. In this review, he does begin to explore the differences between the experiences of young children compared to

adolescents. He reviews some specific clinical problems. These include school phobia[7] and regressive symbiosis[8], non compliance[9], distress[10] related to medical procedures and chemotherapy, cranial irradiation in ALL and bone marrow transplantation. Non compliance with the taking of medication was seen more commonly in older age groups, the mean age of patients who had never missed any doses was 9.5 years compared to 17.4 years for those who had frequently missed doses. In terms of distress, he reported that adolescents exhibited a higher rate of symptomatology especially nausea and vomiting when compared with younger patients. This chapter, therefore is beginning to suggest that differences do exist between the needs of adolescents and younger children.

Grootenhuis (83) described the parents' emotional reactions to a child (between eight and eighteen years) with cancer. Perhaps not surprisingly, she found that mothers and fathers of children who had relapsed reported more feelings of helplessness and uncertainty compared with the parents of children not suffering a relapse. Mothers of children with a relapse also were found to demonstrate more depression and anxiety. The problems of fathers with children with cancer were more difficult to identify and were only revealed with an illness-related questionnaire. The time since diagnosis did not change the

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7 occurs when a child refuses to attend school

8 regressive symbiosis - patients exhibit a group of profoundly regressed behaviours, which include a resumption of bottle feeding, loss of speech milestones, and assumption of foetal positions.

9 Non compliance was seen particularly in the refusal to take medication

10 Distress particularly involving repeated bone marrow aspirations and therapeutic lumbar punctures. It has been suggested that the distress caused by these procedures is in effect much worse than the distress caused by the illness itself.

emotional reactions of any parent. The author also went on to conclude that the parents of children whose cancer had relapsed may require considerable support and should be monitored. Unfortunately in this study there is little consideration of the age of the patient, and a serious weakness of the work would appear to be assuming that reactions across the large age range under consideration were homogeneous.

Hanna (84) reviewed health behaviour among adolescents with cancer. She pointed out the paucity of studies on health promoting and health risking behaviour (e.g. use of alcohol and marijuana) on adolescents with cancer. She concluded the majority of adolescents with cancer engage in the health promoting behaviour of adhering to their treatment, although a considerable proportion were non adherent. A small proportion engaged in drug and alcohol use. She reported that the health behaviour of adolescents with cancer might be influenced by their development. This study again reinforces the need to give special consideration to the care of adolescents in that their needs are different to both adults and children.

Carr-Gregg and Hampson (85) indicate that adolescents suffering from malignancies experience particularly severe psychological distress which in turn distresses medical staff and parents. This again supports the suggestion that the needs of adolescents with malignancies are different to those of young children.

Schowalter J.E., Fernholt J.B., et al (86) presented a particular example of a patient with terminal renal disease in an adolescent who had made a decision

that she wanted to die. They point out that it is almost unique for patients who have not reached adolescence to decide to die. This again reinforces the difference between the needs of adolescents and children.

Hoekstra-Weebers (87) and colleagues went on to investigate distress in parents of adolescents further and used the general health questionnaire to compare 15 parents who had lost younger children (3 - 9 years) with cancer compared to 14 parents who had lost older children (13 - 19 years). They were unable to find any difference in mental health problems between the parents of younger children and those of adolescents. When mental health problems occurred they were reported by father and mother. Their research suggests that special concern should be given to parents of adolescent boys. Parents of adolescents were also less likely to use problem focussing as a method of dealing with their bereavement than the parents of younger children. Again, this may suggest that the needs of parents of adolescents are different if not greater than those of younger children.

Kazak and her colleagues (88) looked at child and parent distress in relation to lumbar puncture and bone marrow aspiration in children with leukaemia. The aim of their study was to develop a valid parent report measure which was aimed to provide parental reports of their child's distress and their own distress. Parents of 144 children and adolescents were involved. Special factor analysis yielded a number of factors which were important :

1. The satisfaction of the parents with the way in which the procedure was handled
2. The distress shown by the child during the procedure
3. The distress of the parents before the procedure
4. The involvement of parents in the procedure

There is little information in the paper about the ages of the patients, although the range (1 month to 17.5 years), mean age (5.8 years) and standard deviation are quoted (S.D. = 4.3). However, from this one can surmise that few older patients were involved in this study. The authors do conclude that there is an inverse relationship between the child's age and the amount of distress measured. This implies that adolescents may require more support before procedures, and again emphasises the need to take a different approach to the management of adolescents compared with children.

Koch (89) looked at parents and their children's (including adolescents) reaction to their child's cancer. The parents main concerns were education and professional development (schooling and absences). This differed from the children and adolescents who were concerned about time pressures, long periods of inpatient treatment, frequent relapses and complications, absence from school and having to repeat school years. Parents were more concerned about the high weekly time burden and unexpected financial pressures. At the same time many parents reported a reorientation of life's priorities which was seen as positive. The analysis was based on 473 mothers and 326 fathers from 504 families. Unfortunately in this study, no distinction was made between the reactions in families with younger and those with older children, although the

study did cover patients up to the age of 18 years. They concluded that financial problems need to be addressed, time needs to be made available by employers to allow them to support their children, and assistance given to mothers in re-entering employment if their child's illness necessitates them leaving their employment for a while. They also suggested that the needs of single mothers in particular need to be addressed, and that specific advice needs to be made available for the children and adolescents themselves and their fathers. In the longer term they suggest that greater and more equitable participation by fathers in the care of their children and adolescents needs to be encouraged.

In a study which included children and adolescents between the ages of 0 and 20 years, Lozowski (90) found that some parents are able to deal with the medical and psychosocial challenges of childhood and adolescent cancer by playing an active and assertive role in the medical treatment process. In her study, 56% reported intervening at some point in the treatment process to prevent or correct a medical mistake. The nature of these interventions included (1) the prevention of erroneous administration of drugs, (2) a need to remind the staff of correct or incorrect procedures, (3) alter intravenous procedures, and (4) mediate the staff's style of interacting with ill children. Parents with high levels of income and education were found to intervene more. From the adolescent perspective, only 20% of those studied were over 11 years old, and of those, only 5% were in the 16 - 20 age group. However, although the numbers were small, the study suggested that parents of older children and adolescents were less likely to intervene, although the authors failed to comment on this finding reported in the results. Again this reinforces the

hypothesis that the needs of adolescents and older children differ in important ways with those of young children.

O'Malley (91) looked at the psychotherapeutic consultation process on the cancer in-patient ward of a hospital in Harvard Medical School, and looked at children in adolescence, aged 8 to 17. He identified some of the obstacles to psychological consultation and reported that the process of such a consultation may in itself lead to obstacles preventing effective intervention. He suggested that there must be willingness on the part of the consultant to alter some of the working practices if effective services to hospitalised children are to be provided.

Ostroff and Steinglass (92) looked at the major issues faced by childhood cancer survivors and described potential parent and medical team factors which were associated with differential adequacy of psycho-social adaptation to childhood cancer survival. They pointed out in work undertaken by Koocher et al. (93) that it had been shown that adolescents report more psychological difficulties than younger children and hypothesised that this may be due to the features of adolescence which feature establishing independence and having to cope with demands and restrictions imposed because of their cancer. Ostroff and Steinglass also introduced a concept of multiple family discussion groups, which were designed to help facilitate more successful transition of adolescent cancer patients and their families from the active treatment to the 'off treatment' phase. They reported this approach as being very promising cost effective approach to long term follow up in adolescents with families welcoming an

opportunity to tell their story and to better understand the impact of cancer on the life of their family.

van Veldhuizen (94) described over-protection as a child rearing attitude in parents of children (aged 9 to 15 years) with life-threatening diseases, and some found that over-protection was used as a coping strategy in such children.

Eiser et al. (95), looked at the impact of limb salvage in-patients with a primary bone tumour. She suggested that the evaluations of patients in this situation should not just be confined to functional measures alone, but extend to the perceived impact of treatment. Her series had a mean age of 17 years (range 8 - 25 years).

4.4.2 Conclusions from the psychological literature:

A number of conclusions can be drawn from this review of the psychological literature, these are as follows:

1. The literature on the psychological impact of cancer in adolescents is thin. At best the needs of adolescents are considered within research or reviews which mainly deal with younger children. Some of the age ranges which are considered are very large. There is therefore a need for specific research to be undertaken looking at the needs of adolescents as a group.
2. Where differences between children and adolescents are described, there do indeed appear to be important differences. These have been described

in the preceding paragraphs and would tend to lend weight to the need to create separate facilities and support for adolescents.

3. The needs of children diagnosed with cancer, as they grow up into adolescents does not seem to be described in any detail within the literature at all. This would appear to be an important area of research which is highlighted by the increased survival of children with cancer.

4.4.3 The Sociological literature

The sociological literature reveals some interesting insights into the experiences of young adolescents with cancer and how their management might be improved. Roberts (96) undertook a study based on the postal questionnaire of 46 adults who had completed, or were still receiving, outpatient treatment for cancer. He found that their concerns were in relation to recurrence, their children's future, potential financial uncertainty, and relationships. He argued that additional psycho-social intervention was required to confront these concerns, and that focus groups in themselves may provide support to young people with cancer. In a second study undertaken by Roberts, (97) he went on to conclude that such groups can help psychological well-being but was unable to demonstrate any change in coping mechanisms or in quality of life.

Pendley (98) looked at the importance of body-image and psycho-social adjustments. She found that concerns about body-image and social anxiety may not develop until several years after treatment. Albaret (99) looked at the differences between males and females and found that girls were less likely to

use coping strategies and confirmed the importance for girls of external family support in contrast to boys use of internal resources.

Dunsmore and Quine (100), in an Australian study, looked at 51 young people aged 12 to 24 with cancer to identify their information support and decision making needs and preferences. They found that the participants in their study wished to be more informed and involved in treatment decisions, particularly in the case of bad news. They also reported the qualities of health professionals that facilitated communications. These included the ability to listen, the ability to express genuine concern, professional expertise, and honesty. In contrast an impersonal manner, the excessive use of technical jargon, haste and the generation gap impaired communication.

Varni (101) in a study of 39 patients with cancer (mean age 17) found that stress management interventions could enhance the quality of life in this group. Stern (102) in a study comparing 48 adolescents with cancer to 40 healthy adolescents from local schools, found that adolescents with cancer are relatively well adjusted but exhibited less positive social sexual self-image than did their healthy peers.

Lynam (103) interviewed 12 young adults with cancer to determine how their illnesses affected relationships with others. They found that maintaining relationships was a priority and this helped them to cope more effectively with their illness, however, they also pointed out that whilst relationships with others were at many times supportive, they could also be stressful.

4.4.4 Conclusions from the sociological literature

The sociological literature provides valuable insights into how effective management may be undertaken in adolescents with cancer:-

1. The principle concerns of adolescents with cancer have been documented and priority could be given to address these in the clinical situation.
2. Support groups are of value improving psychological well-being but that is not necessarily reflected in formal assessments of the quality of life.
3. Differences between males and females may be important
4. The information given to young people should be considered, and how it is delivered and by whom

Stress management techniques may have a role in helping young people to cope with cancer.

4.5 Evidence for the centralised management of cancer

Perhaps the most significant piece of work which has been published recently which has stimulated discussion about the need for centralisation of cancer services was the publication, in April 1995, of the report by the Expert Advisory Group on Cancer to the Chief Medical Officers of England and Wales (the Calman-Hine Report) (104).

This report has been adopted as formal policy by the Secretary of State for England and Wales, and is now one of the key driving forces for implementing change in cancer care at the present time.

One of the principal themes of the Calman-Hine report was the creation of a network of expertise in cancer care, extending from primary care to cancer units in district hospitals to cancer centres. The report also emphasised the centrality of primary care with a patient-centred approach. The Calman-Hine report specifically recommends that cancer centres should undertake the management of rare tumours including those of children and adolescents.

This model of care was a significant development of the pre-existing situation where most cancer management would be undertaken in a district hospital and in relatively few circumstances referrals would be made outwith that unit, with perhaps the exception of patients requiring treatments which were not widely available, e.g. radiotherapy. However, even within the existing framework the access to even basic treatment such as radiotherapy was highly variable (105).

It was envisaged that the Calman-Hine report would lead to a model of care whereby the patient was managed at the most appropriate point within the cancer network, and this would enable the patient to have the best quality of care as close to home as possible.

The Calman-Hine report's philosophy was that the cancer network thus formed should be based on proficiency and not buildings. The Calman-Hine report also emphasised that "services should be planned to minimise travelling times whilst maintaining higher standards of specialist care, using local expertise and agreed protocols ... this network is one of proficiency and not buildings. It may however be appropriate in some areas to relocate or rebuild some facilities to create effective cancer services."

It is important to stress that specialisation is not the same as centralisation. One of the key messages of the Calman Hine report was to stress that clinical teams should allow specialist care to be provided locally.

The issues set out in the Calman Hine Report are clearly highly relevant to providing services for adolescents with cancer. The rarity of adolescent cancers inevitably attracts the proposal that their management should be centralised. However, centralisation potentially can be very disruptive to a young person, particularly in their formative years where contact with friends, education and social networks are highly important. Thus, the purpose of this report is to consider the benefits and disbenefits of centralised model care. One of the key points illustrated by Ferguson (106) was that if centralisation

significantly compromises accessibility then *a priori* outcomes will be worse for the population.

Stiller (107) found that children (defined as under 15 years of age) with certain types of cancer, namely acute non-lymphoblastic leukaemia, non-Hodgkin's lymphoma, Ewing's tumour, Rhabdomyosarcoma, and between 1981 and 1984 osteosarcoma, treated at paediatric oncology centres had significantly higher survival rates than those treated elsewhere. He concluded that children with cancer should be referred to specialist treatment. Further evidence came from a paper published by Pritchard (108) which demonstrated that children with Wilm's tumours who were treated outside paediatric oncology services were subject to over-treatment. Selby *et al* (109) produced evidence to further support the benefits from specialised cancer care in adults and children, but with no reference to adolescents. They concluded that evidence existed to support the various aspects of specialisation (e.g. training, caseload and the formation of multi-disciplinary teams) were strongest for breast cancer, ovarian cancer and some haematological malignancies. They also concluded that there was some evidence to support the conclusion that specialised care can successfully be delivered by a network of district hospitals and main general or teaching hospitals, and does not always require referral to a cancer centre.

In 1994 Stiller (110), published a paper suggesting that survival rates for cancer in relation to patterns of organisation of medical care, specifically treatment at specialist centres or at hospitals treating larger numbers of patients and treatment by protocol (usually within the context of a clinical trial) provided better outcomes. Centralised referral or entry to trials was frequently

associated with a higher survival rate, especially in the less common cancer, and was never found to be associated with lower survival rates. An interesting additional twist to this was found in a study by Sandra Rousch which showed that in Florida socio-demographic factors were associated with the type of facility where a child with cancer was treated (111). Nineteen percent of children in their study were never seen at a cancer centre. These children were likely to be older, with Hodgkin's disease or a brain tumour, reside in a county without a cancer centre or have a higher median income. This latter observation drew the conclusion that in the United States private insurance may be a barrier to referral and protocol-based treatment.

In 1999, Stiller and colleagues (112) published the first evidence about the effectiveness (in terms of survival) or otherwise of centralised management of adolescent cancer. He and his colleagues looked specifically at 879 adolescents and young adults with leukaemias (417 with acute lymphoblastic leukaemia and 462 with acute myeloid leukaemia aged from 15 to 29 years old) and concluded that survival did not vary with the category of hospital, although improvement was shown to have been made over time (from 1984-88, and 1989-94).

4.5.1 Conclusions on the benefits of centralisation for services for adolescents with cancer

The evidence of benefit for the centralisation of care of adolescents with cancer is limited. However, the clear evidence from the management of other cancers is strongly suggestive that the management of rare conditions benefits from centralisation. Furthermore, we do know that many of the features associated with centralised management (e.g. entry into trials) are more prevalent in larger centres. As Stiller has stated, no disadvantage of centralisation has ever been shown.

5. Sources and weaknesses of the data used in the study

5.1 Cancer Registry Data

Cancer has been the subject of a registration system for many years. This means that there is a comprehensive national database on all new cases of cancer. For the purposes of this study data were requested from the Northern and Yorkshire Cancer Registry and Information Service (NYCRIS), based at Arthington House, Leeds.

NYCRIS was formed in April 1997 from the former Yorkshire Cancer Organisation. It brought together the former registries of the Northern and Yorkshire Regions which had hitherto been separate. However, currently the registry only holds accurate data for the former Yorkshire Region. Although, basic registration was carried out in the former Northern Region, the level of investment meant that only a limited amount of information was recorded and that latterly there was a considerable backlog in the registration process at the time of this study. Data were only available up to 1992 for the former Northern Region. Furthermore, the methods of data extraction differed considerably between the registries in the north and south of the region. Yorkshire employed a system using peripatetic clerks, who were directly responsible to the Cancer Registry, whereas in the North, data were recorded by members of the various medical records departments. This inevitably meant that there was a lower level of commitment to cancer registry data recording, and a lower level of expertise in the North compared to Yorkshire.

It was therefore decided not to use the Northern Cancer Registry data because of the weaknesses in the data and due to the unavailability of large amounts of data. However, it has been possible to use another significant source of data which covers the former Northern Region, namely the Northern Region Young Persons' Malignant Disease Registry, based in Newcastle.

5.2 Northern Region Young Persons' Malignant Disease Registry

This registry was established in 1968 in the then Newcastle Region. (113). All consultants were asked to notify the secretary of the Malignant Disease Co-ordinating Committee about all children under their care who were diagnosed as having cancer before their fifteenth birthday. All cases of malignant disease, including neoplasms of uncertain behaviour e.g. histiocytosis X have been included. To ensure completeness, cross-checks are made with hospital-based data (hospital activity analysis, and more recently Korner data set) and the cancer registry. In the early 1980s the data collection was extended to cancers diagnosed up to 25 year olds.

5.3 Differences between the data collection systems in the former Northern and Yorkshire Regions.

There are demonstrable differences between the data collection systems employed in the former Northern Region and the former Yorkshire Region. Although similar data sets have been utilised from both parts of the former region, the data have been kept separate and analysed separately. However, in

the presentation of results some data has been brought together as it could be demonstrated that there were no systematic differences between the Northern and Yorkshire datasets with perhaps one exception, namely the ascertainment of data on epithelial cancer.

The methods of initiation of a cancer registry record in Yorkshire are based on the receipt of a pathology record or in the case of leukaemia a copy report from a haematologist. This means that ascertainment is comprehensive. The pathology report initiates the creation of a data collection form (shown in the appendix) which is then used by the peripatetic clerk to collect additional details from the case records. Pathologists and haematologists are subject to extensive internal and external quality control procedures which provides a considerable degree of confidence that cases of malignancy are not being missed in the cancer registration system.

5.4 Other potential differences in the dataset and possible weaknesses

In the Northern Region the absence of certain routine notification pathways means that the data may be incomplete in certain areas, for example unlike cancer registries, the specialised tumour registry does not receive routine death certificate notification. Although the number of malignancies diagnosed in this way is likely to be extremely low, inevitably some cases will be missed. In Yorkshire during the study period there was only a single case registered solely from a death certificate. In Yorkshire, as well as peripatetic clerks who extract the data from case notes, systems are in place to derive direct notifications from pathology records. Furthermore, cancer registries receive death certificate

notifications from ONS (Office of National Statistics - formerly Office of Population Censuses and Surveys [OPCS]). Data are also (rarely) obtained from direct notifications from general practitioners and other clinicians directly.

It may also be possible that ascertainment in the Northern Region is more complete than the Yorkshire Registry data, given the singular purpose of the registration staff and their accumulated experience.
The existing Yorkshire Children's Tumour Registry based in Leeds (114) already has a system whereby data is exchanged between itself and the cancer registry to ensure completeness. However, currently the data collection for the Children's registry only extends to the age of 15. There are proposals to extend the age range to 25 years.

The following data were requested from both NYCRIS and from the Northern Region Young Persons' Malignant Disease Registry, for the period 1985-1994, for those with malignancies aged 10-24 years old:

Patient identifier

Postcode of residence

Sex

Age at diagnosis

Consultant in charge of case

Clinical diagnosis

Histological diagnosis

Date of diagnosis

Place of treatment

Treatment modalities (present or absent)

Date of death

Cause of Death

The responses to the requests were different and demonstrated the differences in the available datasets and approach. Before any data were released, the author was required to satisfy both NYCRIS and the Northern Tumour Registry of the validity of the proposed study and agree to standard confidentiality clauses.

Occupational data would have been of interest but was not available from either data source. In examining the relationship with disadvantage, proxy measures of social class have been utilised in the Yorkshire data derived from postcodes. This approach will be discussed in greater detail later.

Table 5.4 shows the differences in the available data from the two sources.

Table 5.4 Difference between datasets from Northern and Yorkshire Sources

Data Requested	**NYCRIS**	**Northern Children's Tumour Registry**
Patient Identifier	Available	Available
Postcode of residence	Not available due to confidentiality - electoral ward data available	Not available due to confidentiality - data only provided by county district
Sex	Available	Available
Age at diagnosis	Not produced directly but calculated from other fields	Not produced directly but calculated from other fields
Consultant in charge of case	Not available due to consultant confidentiality - a list of consultants was made available	Not available due to confidentiality
Clinical diagnosis	Available - all as ICD 9	Available ICD 9 until 1990, ICD 10 thereafter
Histological diagnosis ('M' codes)	Available	Available
Date of diagnosis	Available	Available
Place of treatment	Classification of hospitals into three groups	Named hospital data produced
Treatment modalities	Available for first 8 weeks of care	Not included on database
Date and cause of death	Collected systematically and made available	Not collected – but the date of death can be deduced from the data by combining a status of death – with the date of the last known follow up. Cause of death is not recorded but a death is recorded as been due to the malignancy, its recurrence or another cause

The differences between the two sources of data did not produce a major difficulty with the study.

The absence of occupational data meant that it was impossible to directly examine the relationship between occupational class and the incidence of malignant disease. Similarly the absence of treatment data held on the Northern Tumour registry was a limiting factor in performing a regionwide analysis. In the Northern data, geographical location was limited to local authority district of residence, therefore analysis by social class and population density, though technically possible was not undertaken because the results would have been meaningless at this level.

6. Methods

6.1. Choice of Methods

Epidemiology is concerned with the distribution and determinants of disease. Hennekens and Buring (115) have attempted to provide an overview of the types of designs that may be used in epidemiological research. This is shown in Table 6.1 below:

Table 6.1 Overview of Epidemiological Studies

Descriptive Studies	**Analytic studies**
Population (correlational studies)	Observational studies
Individual	Case control studies
Case reports	Cohort studies – retrospective and prospective
Case series	Intervention studies (clinical trials)
Cross sectional surveys	

This classification only provided limited insight into the choice of methodology in order to test the hypotheses set out in section 2.5.2. However, some methodologies to test these hypotheses were clearly impractical e.g. case control study, because of the small numbers involved and the difficulty in being clear about the intervention. The study carried out here is basically a descriptive epidemiological study with an analytic component (the survival analysis). Nested within the study is a qualitative study.

Investigators in the field of cancer have the advantage in the UK (and indeed many other parts of the world) of a long-standing registration system. This system provides comprehensive data on individuals with cancer. Often this rich source of data is under-utilised.

Attempts have been used in this study to utilise health services data. However, it will be seen that this has only been possible to a limited degree. The reasons for this are mainly due to the poor quality of clinical coding data in England. Hospital data in England have mainly been collected for administrative (rather than epidemiological purposes). The introduction of the internal market in England put great focus on data particularly costs. However during this period clinical coding of data remained poor (116). Unlike Scotland, where record linkage has been in place for some time, there is no such linkage between clinical records and death certificates. Again this presents difficulties when undertaking epidemiological research in England. This situation is likely to become worse over the next few years with the new procedures recommended by the General Medical Council to protect confidentiality. The principle being introduced may limit the effectiveness of cancer registration, as it is now required that consent is given by patients to include their data in the cancer registry. However, the Health and Social care modernisation Bill contains a clause (clause 65) which will act as a transitional clause allowing the collection of data by registries without explicit consent for a limited period (personal communication Professor D. Forman).

It was decided for the purposes of this study to make use of cancer registry data. The limitations of this data are considered in this thesis, but it does need to be remembered that registry data of the nature of cancer registries is the envy of those working in many other health fields.

6.2 Classification of Diseases

In any epidemiological study it is essential that in order to allow comparability between different geographical areas and time periods that a standard classification system is used. The standard classification for disease in the world is the International Classification of Diseases, now in its 10th revision (117).

It was Francoise Bossier de Lacroix (1706-1777) who first attempted to classify diseases systematically. William Cullan (1710-1790) from Edinburgh produced a classification of disease which was in common usage at the beginning of the 19-century which was published in 1785 under the title of Synopsis Nosologiae Methodicae. However, it was probably the work of John Graunt on the London Bills of Mortality whose work had taken place over one hundred years beforehand which began the statistical study of disease. Despite his somewhat crude methods, he was able to estimate a mortality rate of 36% in children under the age of six years.

William Farr was appointed to the General Register Office at is inception in 1837, and it was he who made an extremely important contribution to the development of a uniform international classification system. Farr, regularly published his thoughts in the Annual Reports of the Registrar General. Because of his interest, he was asked to prepare proposals for the first international statistical congress, held in Brussels in 1853.(118) Farr's classification was arranged in five groups: epidemic diseases, constitutional (general) diseases, local diseases (according to anatomical site), developmental diseases and

diseases that are a direct result of violence. The congress adopted a compromise list of 138 rubrics. This list was subsequently regularly revised in 1864, 1874, 1880, and 1886.

In 1891 the International Statistical Congress meeting in Vienna commissioned Jacques Bertillon (1851-1922) to prepare a classification of causes of death. The report of Bertillon's Committee was presented to a meeting of the International Statistical Institute in Chicago in 1893. The classification itself was based on earlier classifications of death used in the city of Paris which had been derived from classifications from England, Germany and Switzerland. The Bertillon classification of causes of death was subsequently used widely. In 1898 the American Public Health Association meeting in Ottawa decided to adopt this classification for wide usage in Canada, Mexico and the United States of America.

In August 1900 the French Government held the first International Conference for the revision of the Bertillon or International Classification of Causes of Death. Twenty-six countries were represented at this conference. It was recognised that it was important to revise the classification every ten years, and the French government was therefore requested to call a second meeting in 1910. Revisions were carried out in 1900, 1910 and 1920, under the leadership of Bertillon. He died in 1922.

In 1928 the Health Organisation of The League of Nations published a study (119) which listed the necessary changes to the 1920 International List of Causes of Death that it felt would be required if the classification was to be

used in the tabulation of statistics and morbidity. This lead to the formation of a "Mixed Commission" which had an equal number of representatives from the International Statistical Institute and The Health Organisation of The League of Nations. It was this commission that went on to draft proposals for the fourth (1929), fifth (1938) revisions. Subsequently, sixth, seventh and eighth revisions were published.

In 1975 the Intentional Conference for the ninth revision was convened, which was attended by delegates from forty-six member states. This led to the production of the ninth revision of the International Classification of Disease (120;121). This classification continues to be in use until the present date.

The data collected in this study was initially collected in ICD Version 9. The subsequent publication of ICD 10 in 1990 has led to further improvements and changes in classification of diseases internationally. The changes introduced by ICD 10 are significant, and are discussed in some detail below.

6.3 International Classification of Diseases for Oncology (ICD-O)

The first edition of ICD-O (The International Classification of Diseases Oncology)[11] was published in 1976 (121), with a second edition being published in 1990 (122)

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[11] This is International Classification of Diseases for Oncology, 1st edition Geneva, World Health Organisation 1976. This classification represents an extension of the Chapter.2 of ICD 9 and permits the coding of all neoplasms by topography, histology, morphology and behaviour (malignant, benign, *in situ* of uncertain behaviour or metastatic).

Since the sixth revision in 1948, neoplasms have been classified in chapter two of the International Classification of Diseases, which was largely based on the topographic sites of tumours, whether they were benign or malignant.

Except for a relatively small number of cancers, including lymphatic and haemopoietic cancers, choriocarcinoma, malignant melanoma and certain benign neoplasms there has been no coded nomenclature for histological types.

In 1968, the International Agency for Research on cancer (IARC) was requested by the WHO to make recommendations about the structure and content of chapter 2 of ICD-9. This resulted in the recognition of the need for a uniform histological classification of neoplasms. The MOTNAC coding scheme (Manual of Tumour Nomenclature and Coding) was recommended, which had itself been based on the Systematised Nomenclature of Pathology (SNOP). The successor to MOTNAC became ICD-O.

6.4. Differences in ICD 10 compared to ICD 9 (for malignancies)

ICD 10 for the first time introduced an alphanumeric coding scheme. In ICD 10 the first character in the code is a letter, which is taken from the ICD chapter heading. Thus in ICD 10, the first chapter, chapter A, is certain infectious and parasitic diseases. The letter "C" has been assigned to malignant neoplasms and "D" to benign neoplasms. In the second edition of ICDO the topography section runs from "COO" to "C80".

ICDO 2 is essentially the same as ICDO first edition. However, several new histological types have been introduced and have been coded appropriately, e.g. non-Hodgkin's Lymphoma takes account of the entities recognised in the working formulation published in 1982 (123)

6.5 Differences between ICD-O and ICD 10

Chapter 2 of the ICD is basically a topographical coding system which takes into account the behaviour of the neoplasm. ICD-O has one set of four characters for topography, based on the malignant neoplasm section of ICD 10, and the behaviour code.

There are some important differences between the structure of ICDO and ICD 10. Chapter two of the International Classification of Diseases is essentially a topographical coding system taking into account the behaviour of the neoplasm (malignant, benign or *in situ*). ICDO has one set of four characters for topography, based on the malignant neoplasm section of ICD10, and the behaviour code, incorporating the morphological field.

Thus, if one considers the coding for lung cancer, in ICD 10 it is possible to use five different categories of four characters to describe all the various lung cancer. In ICD-O there is only one topography code for lung (C34.9). The behaviour code is taken into account in the morphology code denoted by the letter "M" which then also changes according to the nature of the tumour, thus

for example in ICDO malignant neoplasm of the lung is coded 34.9, M-8010/3. For a benign neoplasm e.g. adenoma, the code in ICD-O would be C34.9, M-8140/0. In ICD 10 the benign neoplasm would be coded as D40.3.

Only a small number of histological types are identified in ICD. It is therefore impossible to distinguish between an adenocarcinoma of the lung and squamous cell carcinoma of the lung. Both will be coded to C34.9 in ICD 10. In ICDO, adenocarcinoma of the lung would be coded to C34.9, M-8140/3, whereas squamous cell carcinoma would be coded C34.9, M-8070/3.

There are further differences in ICD-O compared to ICD 10. The C81 to C96 session of ICD 10 covers malignant neoplasms relating to lymphoid haemopoietic and related tissues. In ICD-O these are assigned specific morphological codes with behaviour /3 combined with the appropriate topography code in the range C00 to C80. C42 is an unused category in ICD 10 which is used in ICD-0 to designate several topographical sites within haemopoietic and reticulo-endothelial systems. Therefore this category is used principally as topography site for most leukaemias, C42.1 (bone marrow). These are coded C90 - 95 in ICD 10.

6.6 Behaviour Classification

The behaviour code in ICDO 2 is similar to that in the first edition

Behaviour Code	Category	Term
/0	D10-D36	Benign neoplasms
/1	D37 - D48	Neoplasms of uncertain and unknown behaviour
/2	D00 - D09	In situ neoplasms
/3	C00-C76, C80-C97	Malignant neoplasms stated or presumed to be primary
/6	C77 - C79	Malignant neoplasms stated or presumed to be secondary

6.7 International Classification of Childhood Cancer (ICCC)

It is well argued that for children the classification of cancer should be based on morphology rather than in the case of adults. Various systems for the classification of childhood tumours have been used in the past, but Birch Marsden (124) was used for the presentation of data in the International Incidence of Childhood Cancer (125) been widely accepted as standard.

The revised classification for The International Classification of Childhood Cancer was published by the International Agency Research on Cancer (IARC), The International Association of Cancer Registries (IACR), and the International

Society of Paediatric Oncology (SIOP). (126) This classification has been used in this study.

The revised International Classification of Childhood Cancer (ICCC) is based on the ICD-O second edition.

6.8 Method of data analysis

A computerised programme is published in conjunction with the ICCC which allows conversion of data held in ICD 9 to ICD 10, and subsequently to ICCC classification. The data were processed using this computer programme. The results obtained from this process are found in paragraph 2.3 and in figures 7.1 and 7.2. Some of the data necessitated hand coding. Some of the data from Yorkshire included non-malignant codes and these were excluded (for example certain carcinoid tumours). Similarly all CIN III were removed from the data to a separate file, as were data on hydatidiform moles. A brief consideration of these conditions is given in the results section. The Northern Tumour registry did not collect data on these conditions (personal communication - L. More Data manager, Northern Children's' Tumour Registry).

Rates were calculated using the revised population estimates from the 1991 census (127) together with mid year population estimates at district level (Office for National Statistics, unpublished data). The census occurred in the middle of the study period and therefore is likely to provide the most accurate source of population data. Some rates will be shown which have been standardised to World Standard Populations. These data have limitations because World

Standard Populations are not available for the different sexes. However, standardisation to the World Standard Populations (32) is undertaken to provide a broad comparison with studies elsewhere.

Datasets were analysed using a number of software packages. These included Microsoft Excel®, Microsoft Access®, and Stata®.

Stata® allows Poisson exact confidence intervals to be calculated during the standardisation process, and these results are presented. Comparisons are described between the Northern and Yorkshire Region, but analysis has not been undertaken below county district level. Routinely available population statistics were used in calculating incidence and mortality rates.

6.9 Survival Analysis

J.M. Bland and D. Altman reviewed the standard method for calculating survival (128) As they pointed out, analysis of survival data requires special techniques to take account of the fact that 'the event of interest' i.e. death has not occurred in all patients (censoring). Thus for example as in the adolescent cancer data used in this study, where patients were recruited over a ten year period, one patient who was recruited at the beginning of the study might have died after five years, but one recruited two years before the end of the study may be still alive. Thus, because of censoring, the Kaplein Meier method uses a technique, which estimates the probability of being alive at any given time. For example, the chance of remaining alive for two months is the probability of surviving the first month times the probability of surviving the second month, providing that

the first month was survived. The calculations continue until the last event is reached.

A computer is used to calculate these results. There are three assumptions in using this method:

1. The patients that are censored have the same survival prospects of those who continue to be followed.

2. The survival probabilities are the same for subjects recruited early and late in the study. Thus there is a need to guard against changes in case mix over long times periods.

3. It is assumed that the event happens at the time specified. This is not a problem with such a definite event as death, but could be a problem if the event were tumour recurrence. Any delay in identifying this time would bias the survival probabilities upwards.

Normally survival probabilities are presented as a survival curve. The curve is a step function with changes in the estimated probability corresponding to times at which an event (in this case death) occurred. Standard errors and confidence intervals are calculated using Greenwood's method (129).

For the Yorkshire data, survival was calculated for all cases of cancer in 10-24 year olds and the results are shown in section 7.4. A detailed description of the analysis of survival in the Northern Region is contained in Appendix. This has been included in the appendix, as the extent of the analysis was limited

because of the content of the data, and also that the focus of this study was on the experience of adolescents and young people in Yorkshire. Cross references to the findings will be found in the main body of the text.

Survival analysis was performed on 1330 cases of adolescent cancer, aged 10 - 25, occurring in the Yorkshire region between 1985 and 1994. The data set of 1375 cases of cancer was analysed by year, and is shown in the following table. The data suggests that there may have been under-reporting of deaths in 1996 and 1997. The data relating to these last two years was excluded, thus reducing the total number of subjects to 1330. The only point of interest was deaths from any cause with a date of diagnosis acting as the time origin. For each diagnostic group/sub-group the following variables were investigated.

- Sex (male or female), age at diagnosis (10 - 14, 15 - 19, 20 - 24).
- Period of diagnosis 1985 - 1989, or 1990 to 1994.
- Socio-economic status (Carstairs[12] index based on address at diagnosis).
- County of residence (West Yorkshire, Humberside, North Yorkshire).
- Hospital of treatment (centralised or not).
- Treatment modalities (chemotherapy, radiotherapy, operative treatment, hormone treatment).
- Place of treatment was classified as teaching, non-teaching, non-Yorkshire, or private/GP/death certificate only registration.

Individual young people were assigned an area of residence deprivation score as a proxy for their own or their family's socio-economic status based on the

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[12] See Annex 1 for a full discussion of the Carstairs index

validated post code of their address at diagnosis, using the following census variables to calculate the Carstair's index (130) These variables include:

- percentage of unemployed male residents over 16
- residents in social class 4 and 5
- non-car ownership
- over-crowding

Each address was linked to its census electoral ward by the central postcode directory. Carstair's index was then calculated for each electoral ward (n= 536) with data derived from the 1991 census. The Carstair's index was then characterised into fifths into the entire study population, with scores ranging from minus 5.69 (most affluent) to 17.63 (least affluent). Survival rates (in years) were calculated using Kaplan-Meier methods (131)). Carstairs analyses were not performed below county level due to the small numbers of deaths at that level. Data were modelled using Cox's proportional hazard techniques (132). Hazard ratios (HR) and levels of significance were then reported. Hazard ratios are the ratio of the hazards (probability of dying at time 't', having survived at that time) for two different values of a co-variate, and can be interpreted in a similar way to relative risks. In order to retain power, the data was grouped into the following groupings:

all cancers

- germ cell tumours (due to the small numbers it was not possible to split these categories to any useful effect)
- carcinomas
- leukaemias
  - acute myeloid leukaemia (AML)

acute lymphoblastic leukaemia (ALL)

- Hodgkin's Disease
- Non-Hodgkin's lymphoma
- CNS tumours
- Bone tumours

Level of significance was set at 5%, with key value of 0.05 or less, indicating a statistically significant effect. Statistical analyses were performed using STATA.(133)

Survival curves were tested for significance using a log rank technique.(134) Counties were used as the level of geographical analysis.

The choices which were considered for the analysis of location were as follows:

- Postcode sector
- Electoral ward
- Local authority district
- Health Authority area
- County
- Other non administrative boundary

After consideration, counties were selected as the geographical basis for analysis. The reasons for this are considered below:

Postcode sector: Postcoded data were not supplied as it was deemed to be 'identifiable data' and therefore because of the registries' protocols for release of data, could not be provided. Although analysis at postcode sector would have not been sensible due to small numbers, postcoded data would have allowed a number of more sophisticated geographical analyses – for example it would have enabled precise distances between residences and cancer centres to be calculated. (N.B. the transformation of postcoded data to electoral wards referred to in the methods section was carried out by the cancer registry).

Enumeration districts/ local authority wards/ local authority districts

The problem with these geographical areas relates to the small numbers. In the Northern and Yorkshire Region some of the local authority districts are as small as 40,000. This size of population is likely to yield only six cases per year (based on an assumed incidence of 150 per million per year).

Health Authority Districts

Health Authority districts were considered, but rejected because of the difficulties arising from the changes in health authority boundaries over this ten-year period. Most health authority boundaries were changed once, some twice.

County Boundaries

County boundaries were felt to be the most appropriate geographical boundary, In the Northern and Yorkshire Region, apart from the creation of unitary authorities, these have remained relatively unchanged since 1974. It was also important in this piece of work to ensure that the analysis was relevant to appropriate administrative boundaries - particularly to those of health authorities. It is health authorities that would make any investment decision involving the future of cancer services. Health authorities in the region could be clearly assigned to county boundaries.

Non administrative boundaries were also rejected (latitude, longitude) because of the lack of clear relevance to organisations making investment decisions.

Time period

Smaller administrative boundaries could have been utilised had the time period been extended. A ten-year time period was estimated to provide sufficient cases to allow meaningful analysis in the region. In spite of this there was concern from some of the clinicians that the period of the study was extending over too great a length of time, and would have preferred the study to be more contemporary than it eventually was.

6.10 Qualitative Study of the Priorities and Experience of Young People with Cancer

6.10.1 Background and Introduction

Qualitative research is a frequently used technique in the social sciences. Unlike quantitative research, qualitative methods do not provide quantified answers to research questions. The objective of qualitative research is to identify areas of interest or concern and to give emphasis to the meanings, experiences and views of the participants.

Holloway and Wheeler describe the following as the main features of qualitative research. (135)

1. Qualitative research takes the 'emic' perspective, the insider's point of view. (136)
2. Researchers immerse and involve themselves in the setting and the culture under study. Often qualitative research is called 'naturalistic enquiry'. (137)
3. The data have primacy; the theoretical framework is a consequence of the data and is not derived *a priori.* Fetterman claims that the researcher enters the field with an open mind, not an empty head. (138)
4. The method involves 'thick description'. Immersion in the setting may involve portrayals of the participants' experiences, which is likely to be more than just a report of their experiences. It may, for example include verbatim quotations from the individuals under study. Denzin (139) describes thick description as 'deep, dense, detailed accounts of problematic experience. It

presents detail, context, emotion and the webs of the social relationship that join persons to one another.'

5. The relationship between researcher and the subject of study is close, much more so than in quantitative research.
6. There is an interaction between data collection and analysis. In qualitative research a hypothesis is rarely established at the outset, therefore qualitative researchers need to be constantly appraising the data and reformulating working propositions.

The relationship between qualitative and quantitative research

Traditionally, natural science has employed quantitative methods. It has its basis in 'positivism' - an approach to natural science based on a belief in universal laws and insistence on objectivity and neutrality (140). It was in the 1960s that the traditional view of this scientific approach began to be challenged, and the contrast between this and the sociological perspective began to be more clearly defined (141). Interestingly, this was linked back to the work earlier in the twentieth century by Mead (13). A more interpretative paradigm has a long history, but has begun to develop currency in recent decades.

Corner (142) warns the researcher not to be simplistic about assumptions of social science or to overemphasise the difference between the methods. The two approaches are merely different ways of using research pragmatically. Sometimes techniques are combined as in a paper published by Dolan (143) and others in which the basic study design was qualitative, but used some

quantitative techniques to formally compare results of changes in views of members of the public over time concerning priority setting in the health service.

These differences may be used to advantage using a technique called 'triangulation', where several methods may be brought together in the study of one phenomenon. Two qualitative methods will be employed in this study; focus groups and interviews, at the same time 'thick description' will be produced from fieldwork in the clinics. This thesis also employs a nested strategy, where a qualitative piece of work complements a quantitative study, both aspects of the study being essential to determine the nature of care of adolescents with cancer.

One of the concerns in studying the experiences and aspirations of people with cancer is that the research process could cause potential distress interfere with the doctor patient relationship. A study undertaken by Davies and colleagues (144) found that for both patients and carers, the interviews were viewed very positively and were said to have helped, though in 5% of cases this was not so. On 3% of occasions the interviewer found additional information which was communicated to the clinical team, a change in management was said to have occurred in less than half of these instances. Thus conducting interviews, in general probably does no harm to the vast majority, it does need to be recognised that in some instances some distress can be caused.

6.10.2 The nature of the qualitative study with adolescents

In delivering care to young people, it is clearly important to decide what parameters are important as well as survival. These might include such factors as educational achievement, access to friends, access for parents, internal environment. A further factor to consider is how these factors might be valued differently by different aged adolescents. Parents and/or spouses/partners will also have views on priorities and need to be taken account of in planning services.

The published literature gives very few clues about what is important about their care for young people with cancer. This project aims to delineate those parameters and to gain understanding of how priorities are assigned by age. This information will then be crucial for the development of an ongoing monitoring tool.

The experience of young people who have been managed both inside and outside the adolescent unit will be assessed.

6.10.3 Methodology and Research Design

The study is divided into two phases. Phase one consisting of a series of focus groups and phase two comprising a number of structured interviews. All the material used in the qualitative study is contained in the appendix (data collection instruments, consent forms, information sheets). A transcript of one of the interviews is also contained in the appendix.

6.10.3.1. Phase I - Focus Groups

Four focus groups were held to identify issues amongst patients, young people and professionals. Two focus groups were held with patients in the adolescents' and children's oncology unit at St. James' Hospital, Leeds. One focus group comprised normal healthy adolescents and took place at a comprehensive school in North Yorkshire. The focus group for professionals not involved in the care of adolescents with malignant disease in a cancer centre was undertaken at a small hospital in North Yorkshire.

6.10.3.2 Phase II - In-depth interviews

After the four groups had taken place, in depth interviews were carried out in the outpatient clinic at St James' with patients and their parents/sponsors to identify the importance of the previously identified parameters. Interviews were carried out with patients until themes are repeated. A mix of patients was obtained ensuring that the views of patients treated in the adolescent oncology unit and in other setting were included, but was limited by the patients in the ward at the time and not all felt able to take part because of the effects of their illness and treatment.

6.10.4 Entry Issues, ethical considerations and recruitment

Ethical approval for the study was obtained from the St. James Hospital Leeds Ethical Committee. Patients were invited to take part in the study, the details of which were explained to them by a senior nurse or the candidate. Most patients approached agreed to take part, but some felt unable to participate because of

their illness. The sizes of the focus groups were smaller than originally planned because of the number of patients available at any one time in the ward.

6.10.4.1 Focus Groups

Professionals: Professionals from a peripheral hospital formed a discussion group.

Patients: Two groups of patients were recruited with appropriate consent and took place in the inpatient unit. One patient who was unable to take part because of her illness provided written material based on the 'prompt' questions used in the focus groups.

Normal Adolescents: A focus group of young people not affected by serious disease took place at a site away from the hospital, in a comprehensive school.

6.10.4.2 Phase II Recruitment

Patients and their parents were interviewed in the outpatient oncology unit clinic. In advance of the clinic, all patients were informed of the study and when arriving for the clinic appointment were invited to take part. Not all those who had agreed to take part in this phase of the study were interviewed.

6.10.4.3 Consent

Phase I: The purpose of the focus groups was explained in detail to those taking part by the use of a number of information sheets. At the outset of each

focus group, the purpose of the study was explained and those attending were given the opportunity to withdraw from the study if required.

Phase II: In advance of the clinic, patients were informed that the study was taking place through an information sheet. All patients attending the clinic were asked to give consent and the purpose of the study explained.

6.10.4.4 Data Collection and Analysis:

The candidate carried out the focus groups and interviews. Focus group interviews were recorded using a cassette tape recorded and transcribed. Independent evaluations of the transcripts were performed. These were undertaken by a colleague consultant in public health who independently read the transcripts and listed the main themes. These were then compared with the themes identified by the thesis author.

6.10.4.5 Payment of Expenses

No payment of expenses was made

6.10.4.6 Information Sheets

Information sheets, describing the study were produced and made available at the focus groups and at the clinic where in-depth interviews took place. The results of the qualitative study are to be found in the results section at 7.8

7 Results

A computerised programme is published in conjunction with the ICCC which allows conversion of data held in ICD 9 to ICD 10, and subsequently to ICCC classification. The data were processed using this computer programme. For Yorkshire, of the 1,482 records which were processed, 621 were successfully coded electronically to ICD 10, the remaining 861 were coded manually. The data file was then re-processed to ICD 10, this produced 437 errors, 334 were unrecognised morphology codes, 143 records were benign of unspecified type, 634 records were coded satisfactorily, and 1 record was recommended for more specific coding. All these errors were examined individually and ICCC codes applied individually. The results of the final coding are shown in Figure 7.1 (Yorkshire) and Figure 7.2 (Northern).

Figure 7.1

DATA – CODING FLOW CHART.

YORKSHIRE

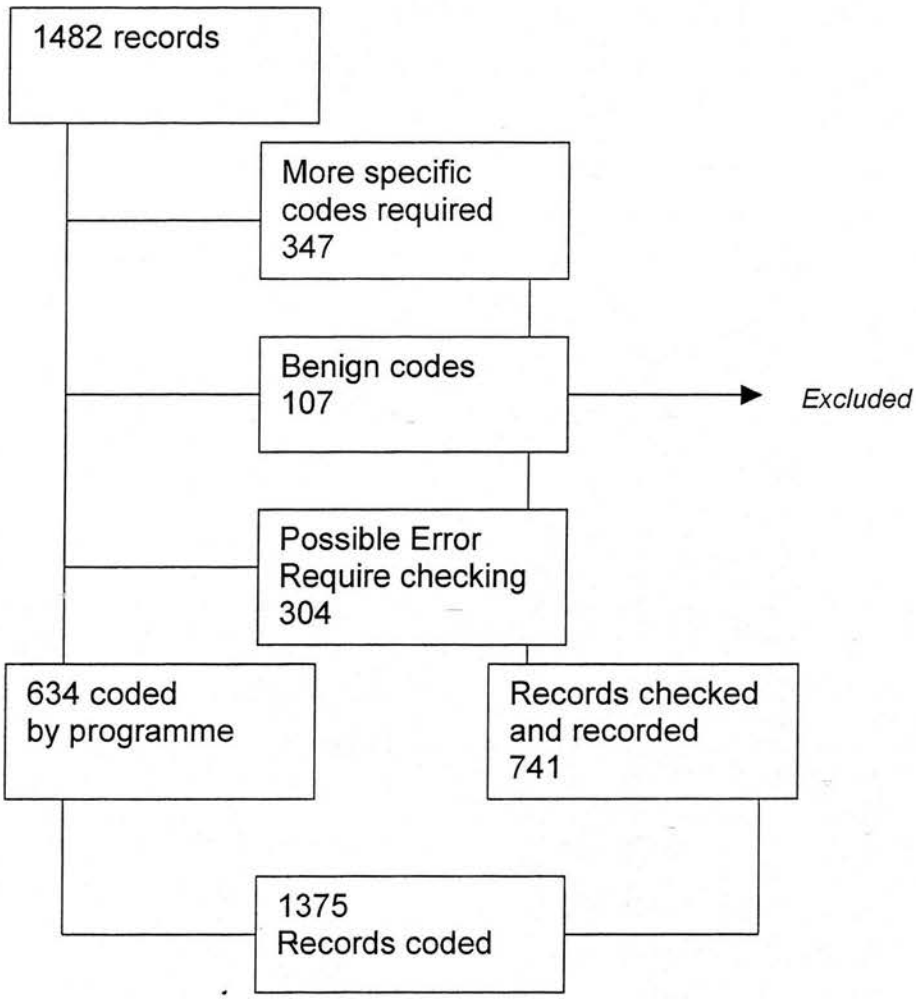
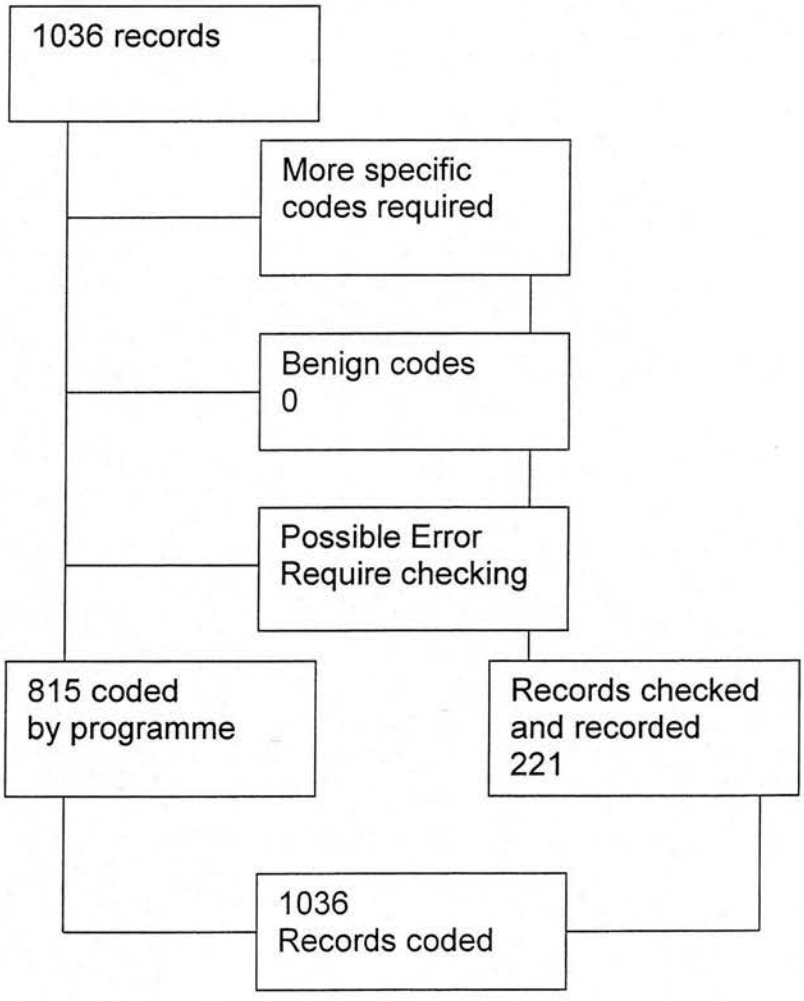


Figure 7.2

DATA – CODING FLOW CHART.

NORTHERN



The same process was undertaken for the data from the Northern Children's Tumour Registry and of the 1036 records, 221 were identified as requiring special checking, no benign codes were identified, and no records required more specific checking. This meant that 815 records had been successfully coded by the ICCC software, and 221 records required coding by hand. This was therefore a noticeable difference between the Northern data set and that from Yorkshire, and is suggestive of an improved quality in the data set in the Northern data than compared to Yorkshire, and may suggest that specialist tumour registries are more accurate than data from cancer registries.

7.1 Incidence Rates in Northern and Yorkshire Region compared to England and Wales

This study was undertaken on all young people between the ages of 10 and 25, resident within the boundaries of the Northern & Yorkshire Region. During the study period there have been a number of changes to the configuration of Regions in the area. South Cumbria, which was formerly part of the Northern Region, transferred to the North-West Region. South Humber Health Authority, which had previously been part of the Yorkshire Region, transferred to Trent. For the purposes of this study, the populations of these two areas have been included in the study population. The population of the area under study was 6.77 million, of which 3.09 million were resident in the former Northern Region, and 3.68 million resident in the former Yorkshire Region. The landmass covered in this study extends from the Scottish border, including the whole of Cumbria, and extends to the south of the river Humber. It covers an area which

contains two Regional Centres, Leeds and Newcastle, and also other major cities, such as Carlisle, Durham, Middlesbrough, York, Hull, Wakefield, Huddersfield. The area includes extensive rural areas, such as those in the northern part of Northumberland and in North Yorkshire.

Table 7.1: Population (all ages) of the Northern and Yorkshire Region - Population Estimates 1991

Region	Population - all ages (000s)
Northern	3091.7
Yorkshire	3680.9
Total	6772.6

Source 1991 Census

Table 7.2: Cases of Cancer in Adolescents and Young Adults by Region and Age group 1985 - 1994

Age group Region	10-14	15-19	20-24	Totals
Northern	186	333	517	1036
Yorkshire	255	417	703	1375
Total	441	840	1220	2411

Of the 6.77 million residents of the extended region, 1,346,200. Were aged between 10 and 25 (19.89%). During the 10-year period, 1985 - 1994, a total of 2,411 cancers were recorded (1241 in boys and 1170 in girls). Table 7.2 shows the distribution of cases by former region over this period, illustrating that approximately 100 cases of cancer in this age group is found in the Northern Region and around 138 new cases each year in the former Yorkshire Region.

Table 7.3: Age specific incidence rates for all cancers per million person years (Standardised to World Standard Populations- truncated to 10-24)

Age group	10-14	15-19	20-24	Age Standardised Totals
Male	133	186	200	173
Female	116	176	208	165

Table 7.3 shows the standardised incidence rates for all cancers in the extended region per million population. These figures are broadly compatible with other similar studies. The excess cancer in boys has been noted previously. The rising trend in cancer rates by age group is also clearly illustrated by these figures.

7.2 Numbers of Cancers in Young People in the Northern and Yorkshire Region

Graphical and tabular presentation is given as follows of cancer by age group as follows:

Cancer in Young People in Northern and Yorkshire Region (numbers) figure 7.3, table 7.4

Cancer in Young People in Northern and Yorkshire Region (percentages) figure 7.4 table 7.4

Cancer in Young People in Northern Region (numbers) - figure 7.5 table 7.5

Cancer in Young People in Northern Region (percentages) - figure 7.6 table 7.5

Cancer in Young People in Yorkshire Region (numbers) - figure 7.7, table 7.6

Cancer in Young People in Yorkshire Region (percentages) - figure 7.8, table 7.6

Cancer in Young People in Northern and Yorkshire Region by individual age group. Figures 7.9 – 7.12

Figure 7.3

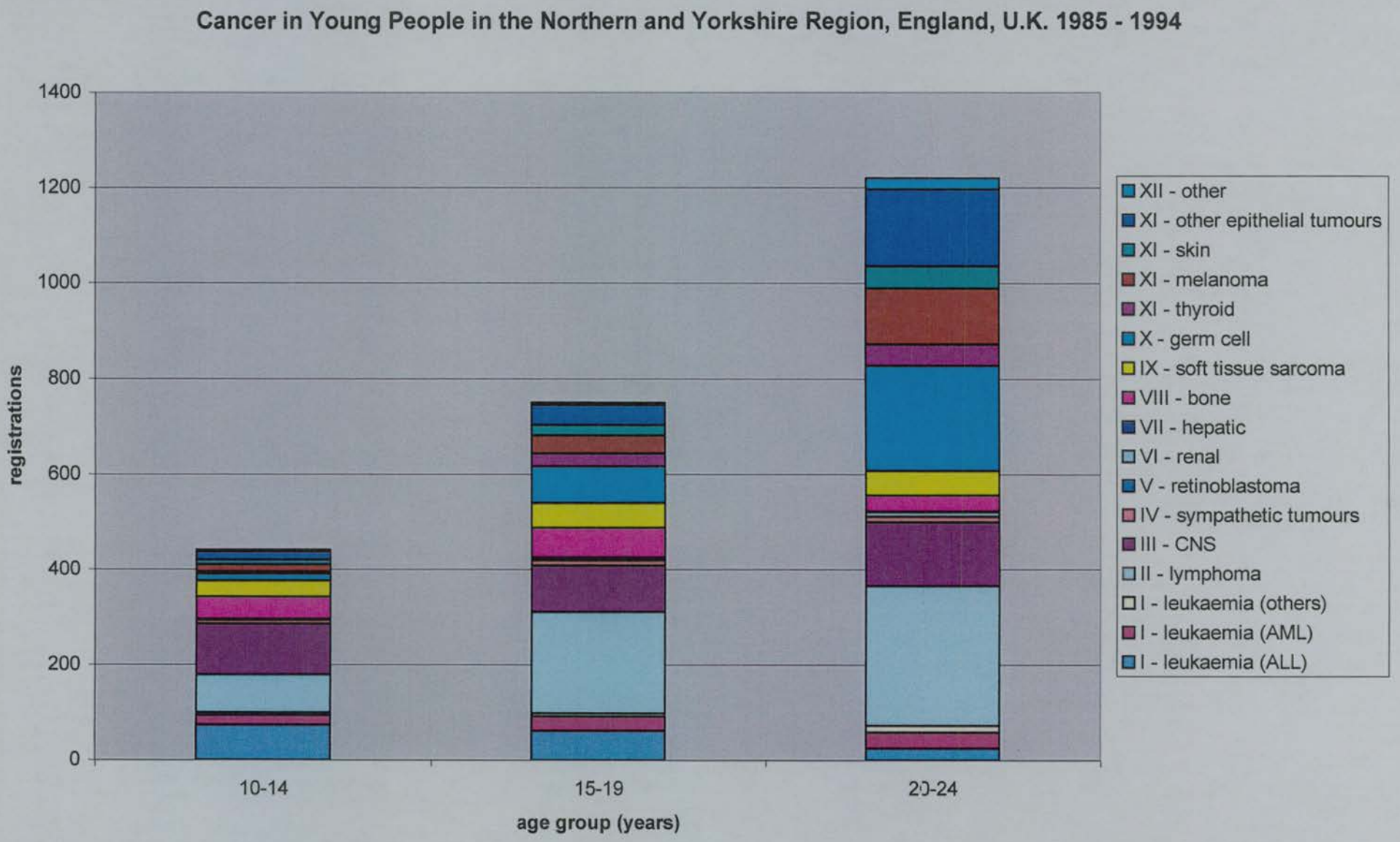

Cancer in Young People in the Northern and Yorkshire Region, England, U.K. 1985 - 1994
registrations
1400
1200
1000
800
600
400
200
0
10-14
15-19
20-24
age group (years)
XII - other
XI - other epithelial tumours
XI - skin
XI - melanoma
XI - thyroid
X - germ cell
IX - soft tissue sarcoma
VIII - bone
VII - hepatic
VI - renal
V - retinoblastoma
IV - sympathetic tumours
III - CNS
II - lymphoma
I - leukaemia (others)
I - leukaemia (AML)
I - leukaemia (ALL)

Figure 7.4

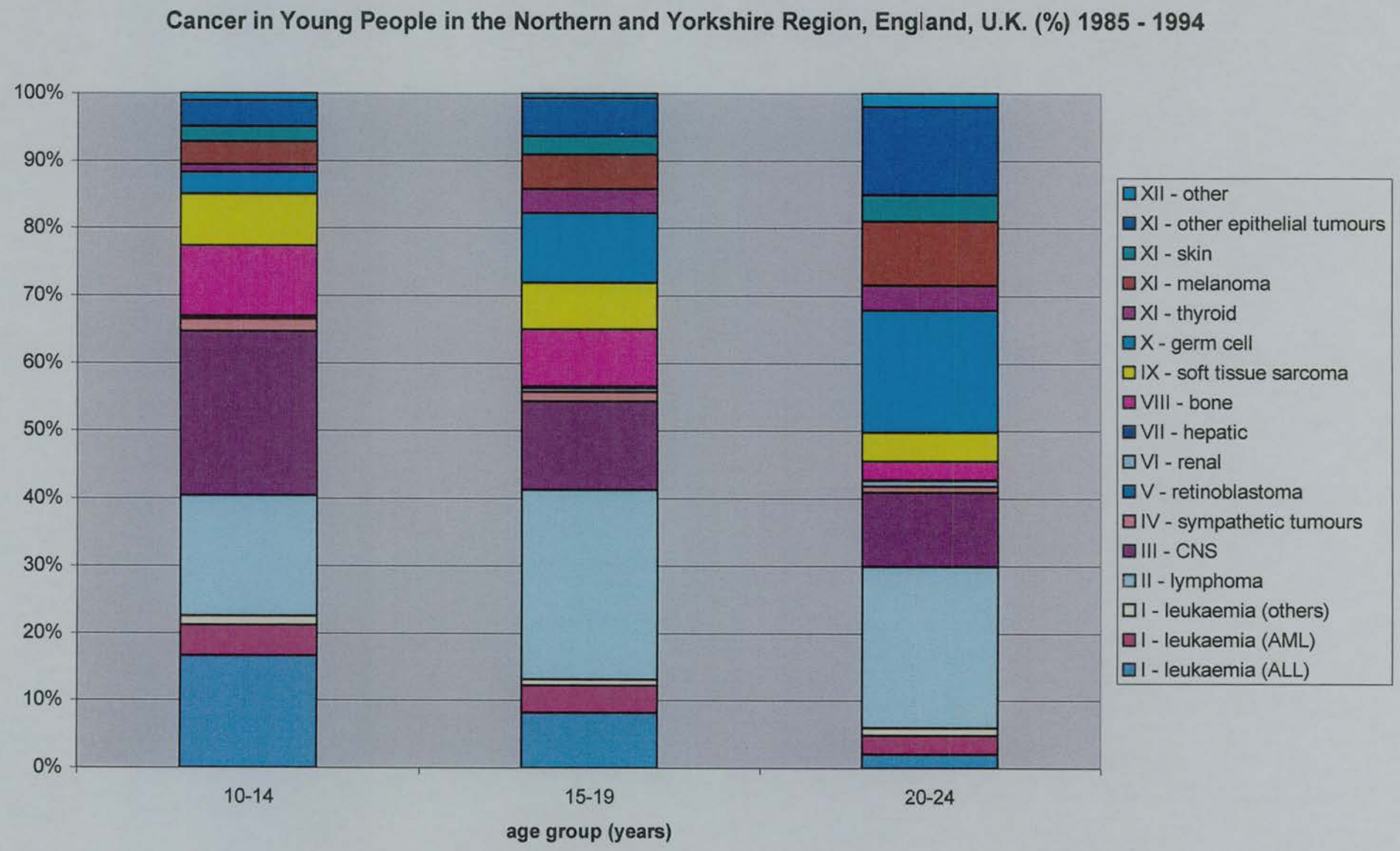

Cancer in Young People in the Northern and Yorkshire Region, England, U.K. (%) 1985 - 1994
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
10-14
15-19
20-24
age group (years)
XII - other
XI - other epithelial tumours
XI - skin
XI - melanoma
XI - thyroid
X - germ cell
IX - soft tissue sarcoma
VIII - bone
VII - hepatic
VI - renal
V - retinoblastoma
IV - sympathetic tumours
III - CNS
II - lymphoma
I - leukaemia (others)
I - leukaemia (AML)
I - leukaemia (ALL)

Figure 7.5

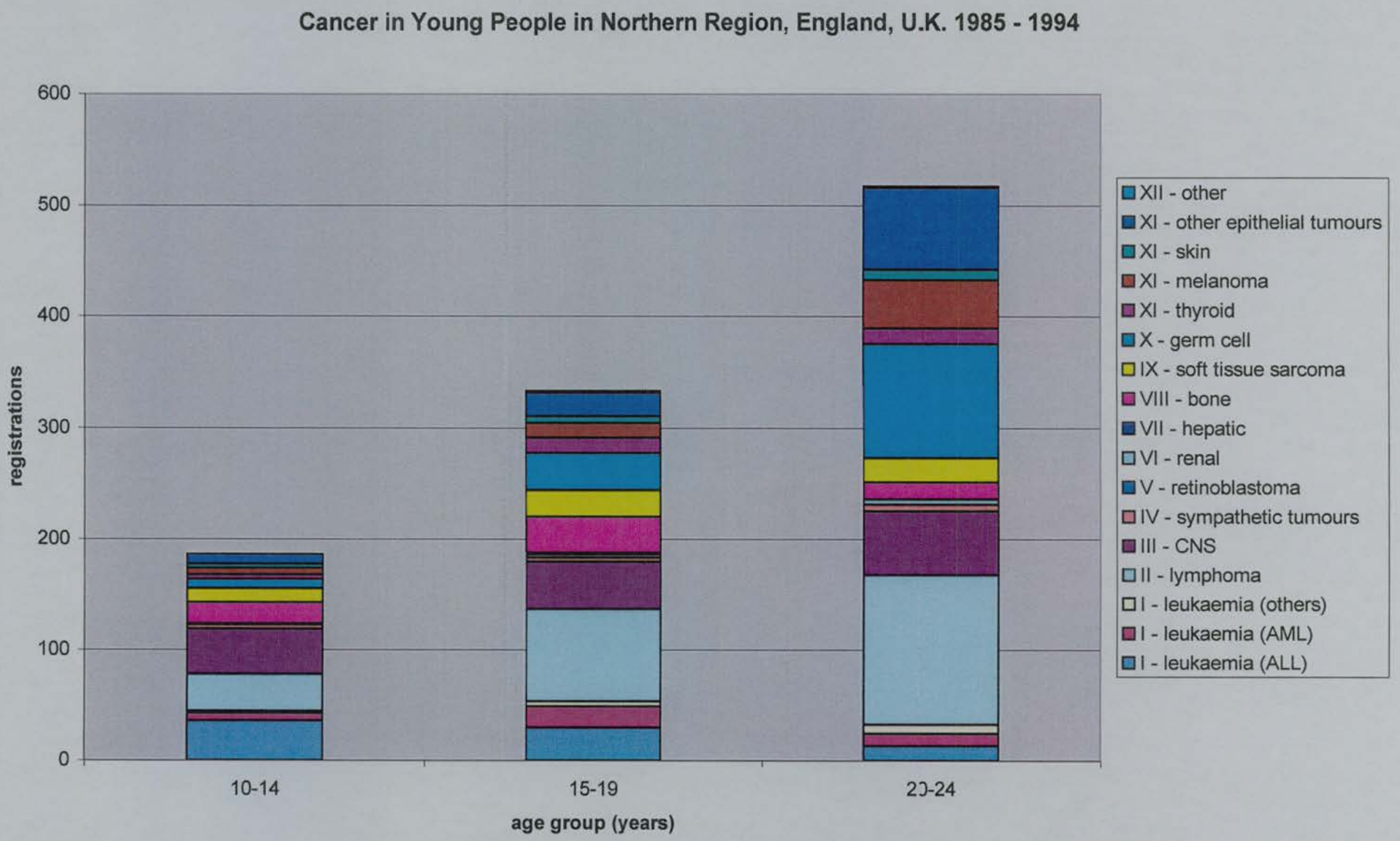

Cancer in Young People in Northern Region, England, U.K. 1985 - 1994
600
500
400
300
200
100
0
registrations
10-14
15-19
20-24
age group (years)
XII - other
XI - other epithelial tumours
XI - skin
XI - melanoma
XI - thyroid
X - germ cell
IX - soft tissue sarcoma
VIII - bone
VII - hepatic
VI - renal
V - retinoblastoma
IV - sympathetic tumours
III - CNS
II - lymphoma
I - leukaemia (others)
I - leukaemia (AML)
I - leukaemia (ALL)

Figure 7.6


Cancer in Young People in Northern Region, England, U.K. (%) 1985 - 1994
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
10-14
15-19
20-24
age group (years)
XII - other
XI - other epithelial tumours
XI - skin
XI - melanoma
XI - thyroid
X - germ cell
IX - soft tissue sarcoma
VIII - bone
VII - hepatic
VI - renal
V - retinoblastoma
IV - sympathetic tumours
III - CNS
II - lymphoma
I - leukaemia (others)
I - leukaemia (AML)
I - leukaemia (ALL)

Figure 7.7

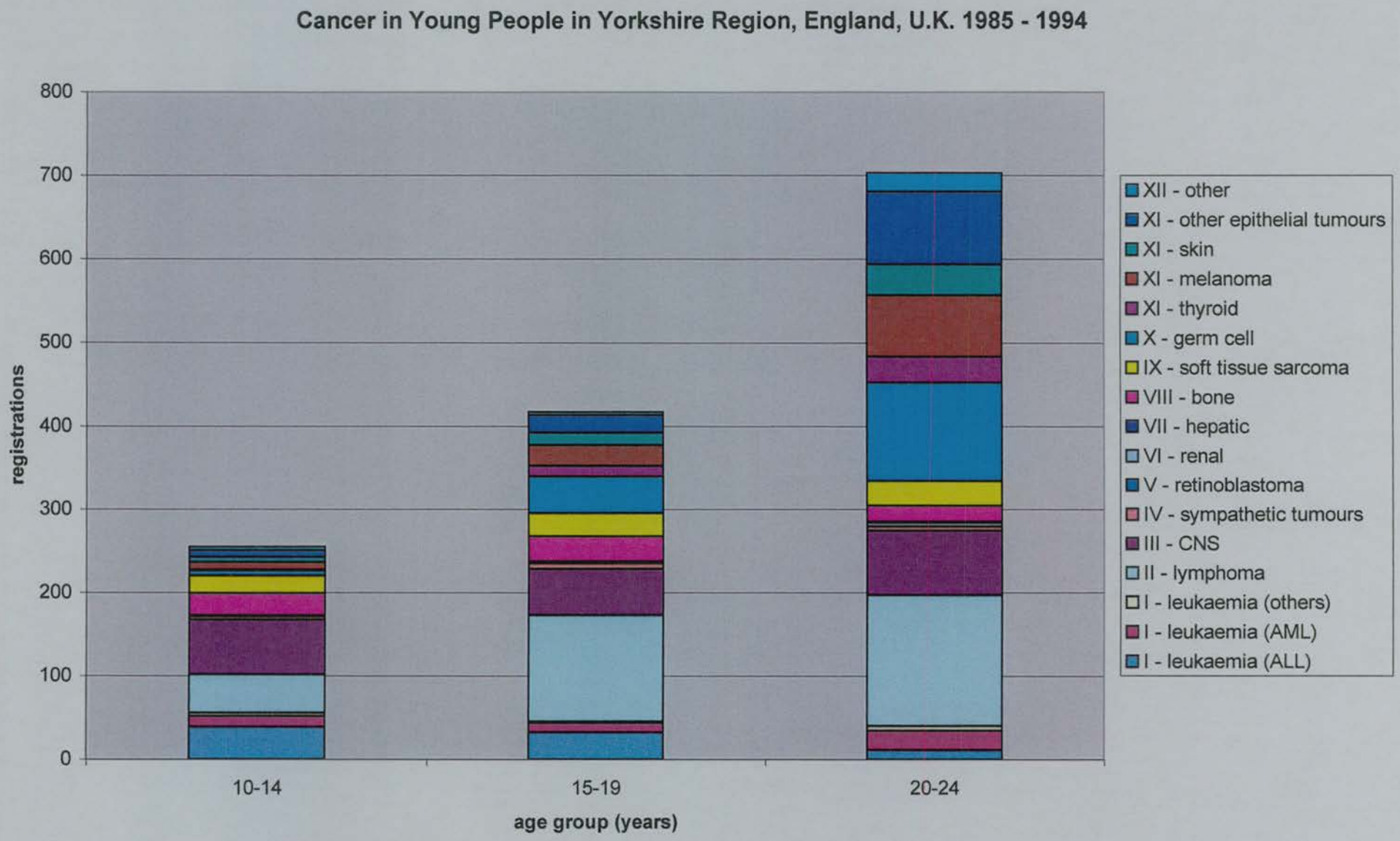

Cancer in Young People in Yorkshire Region, England, U.K. 1985 - 1994
800
700
600
500
400
300
200
100
0
registrations
10-14
15-19
20-24
age group (years)
XII - other
XI - other epithelial tumours
XI - skin
XI - melanoma
XI - thyroid
X - germ cell
IX - soft tissue sarcoma
VIII - bone
VII - hepatic
VI - renal
V - retinoblastoma
IV - sympathetic tumours
III - CNS
II - lymphoma
I - leukaemia (others)
I - leukaemia (AML)
I - leukaemia (ALL)

Figure 7.8

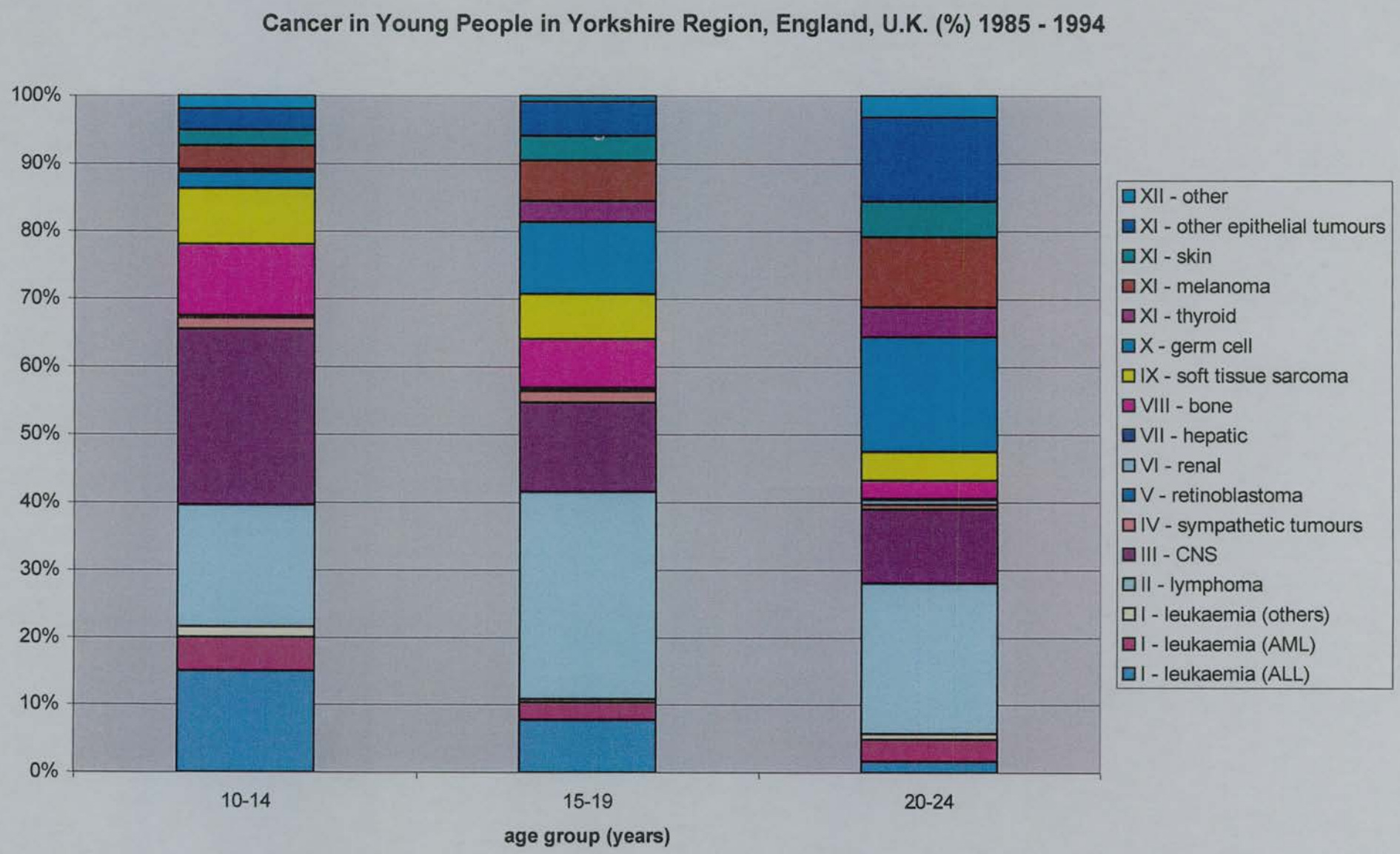

Cancer in Young People in Yorkshire Region, England, U.K. (%) 1985 - 1994
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
10-14
15-19
20-24
age group (years)
XII - other
XI - other epithelial tumours
XI - skin
XI - melanoma
XI - thyroid
X - germ cell
IX - soft tissue sarcoma
VIII - bone
VII - hepatic
VI - renal
V - retinoblastoma
IV - sympathetic tumours
III - CNS
II - lymphoma
I - leukaemia (others)
I - leukaemia (AML)
I - leukaemia (ALL)

Figure 7.9

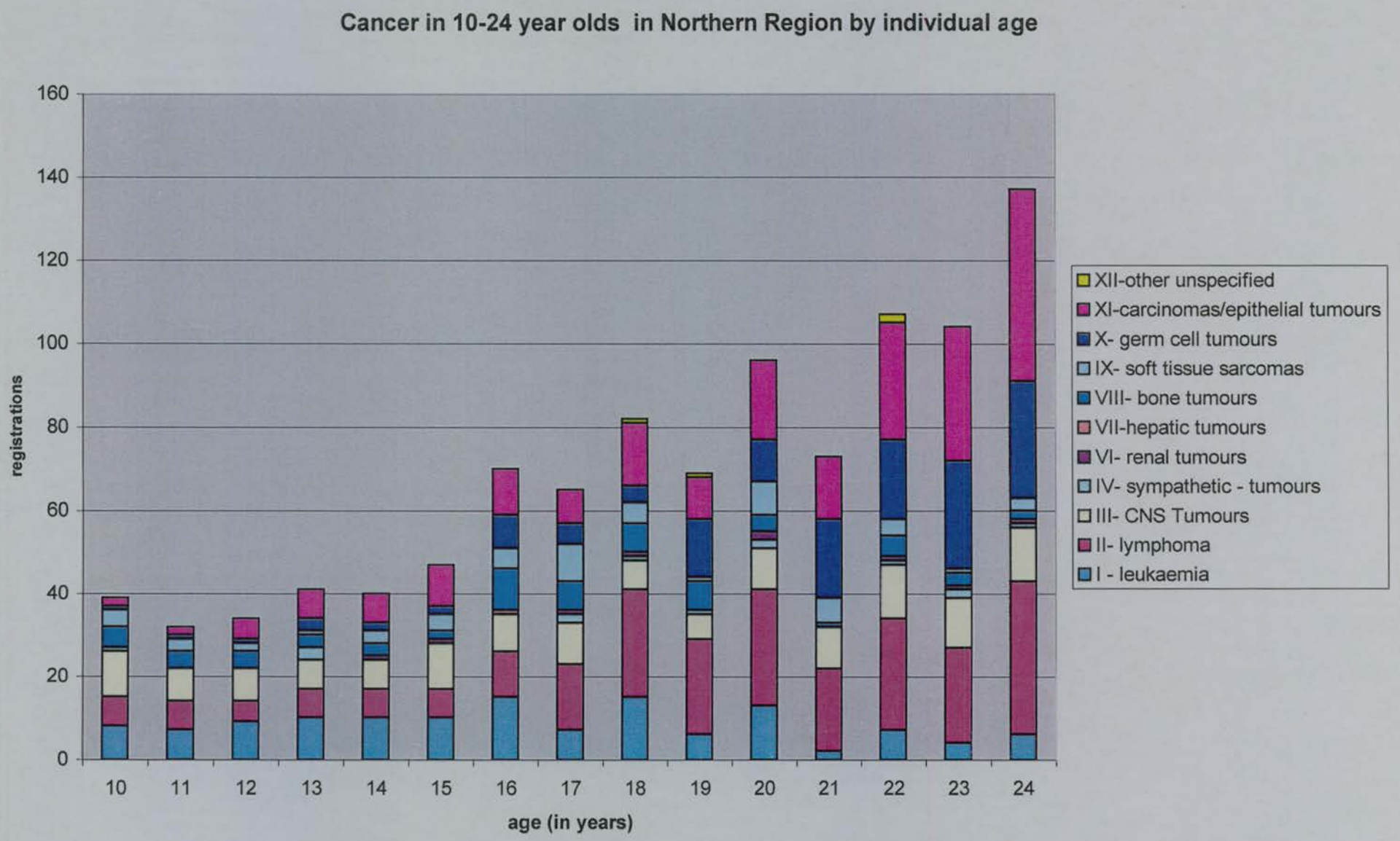

Cancer in 10-24 year olds in Northern Region by individual age
registrations
160
140
120
100
80
60
40
20
0
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
age (in years)
XII-other unspecified
XI-carcinomas/epithelial tumours
X- germ cell tumours
IX- soft tissue sarcomas
VIII- bone tumours
VII-hepatic tumours
VI- renal tumours
IV- sympathetic - tumours
III- CNS Tumours
II- lymphoma
I - leukaemia

Figure 7.10

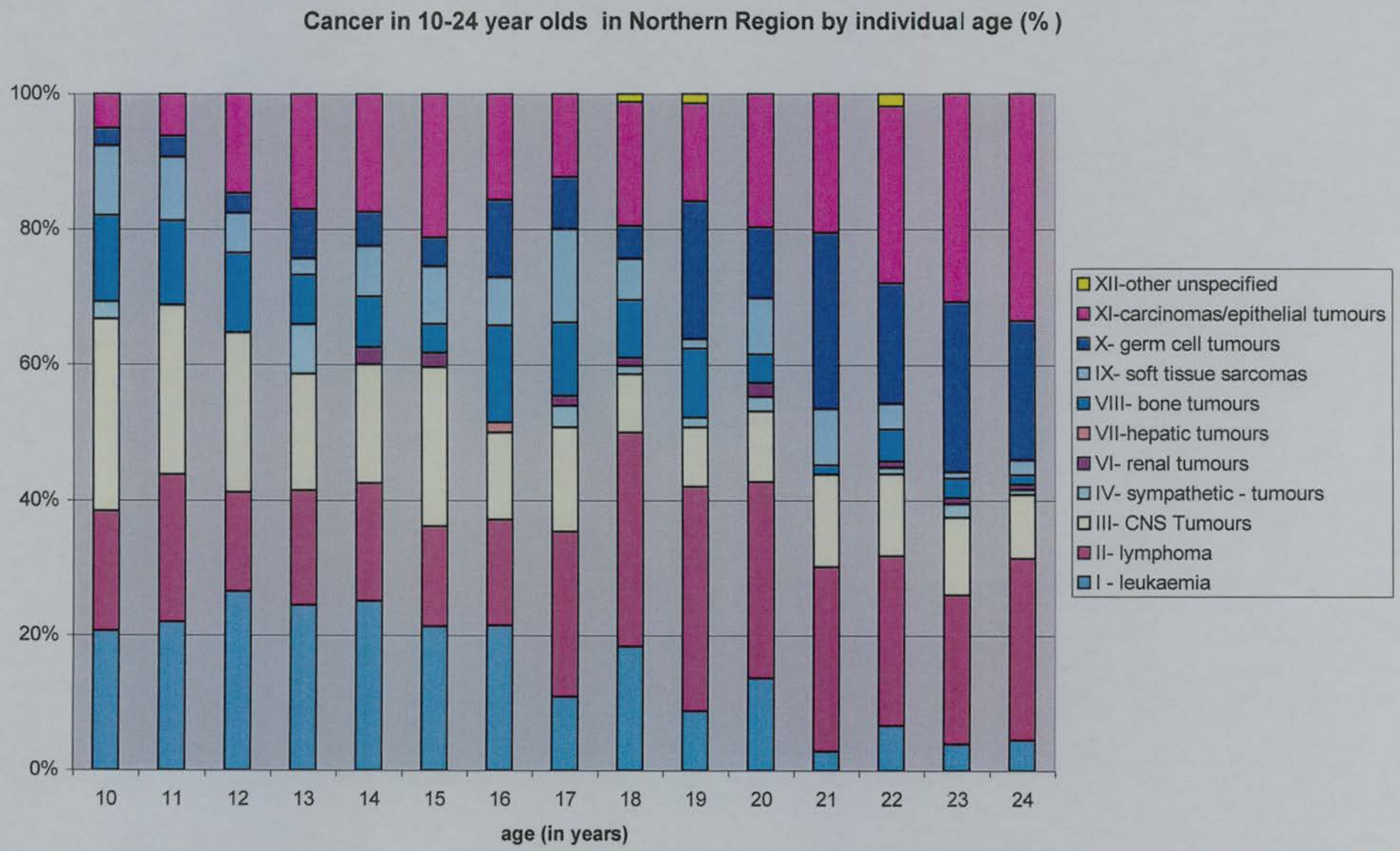

Cancer in 10-24 year olds in Northern Region by individual age (%)
100%
80%
60%
40%
20%
0%
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
age (in years)
XII-other unspecified
XI-carcinomas/epithelial tumours
X- germ cell tumours
IX- soft tissue sarcomas
VIII- bone tumours
VII-hepatic tumours
VI- renal tumours
IV- sympathetic - tumours
III- CNS Tumours
II- lymphoma
I - leukaemia

Figure 7.11

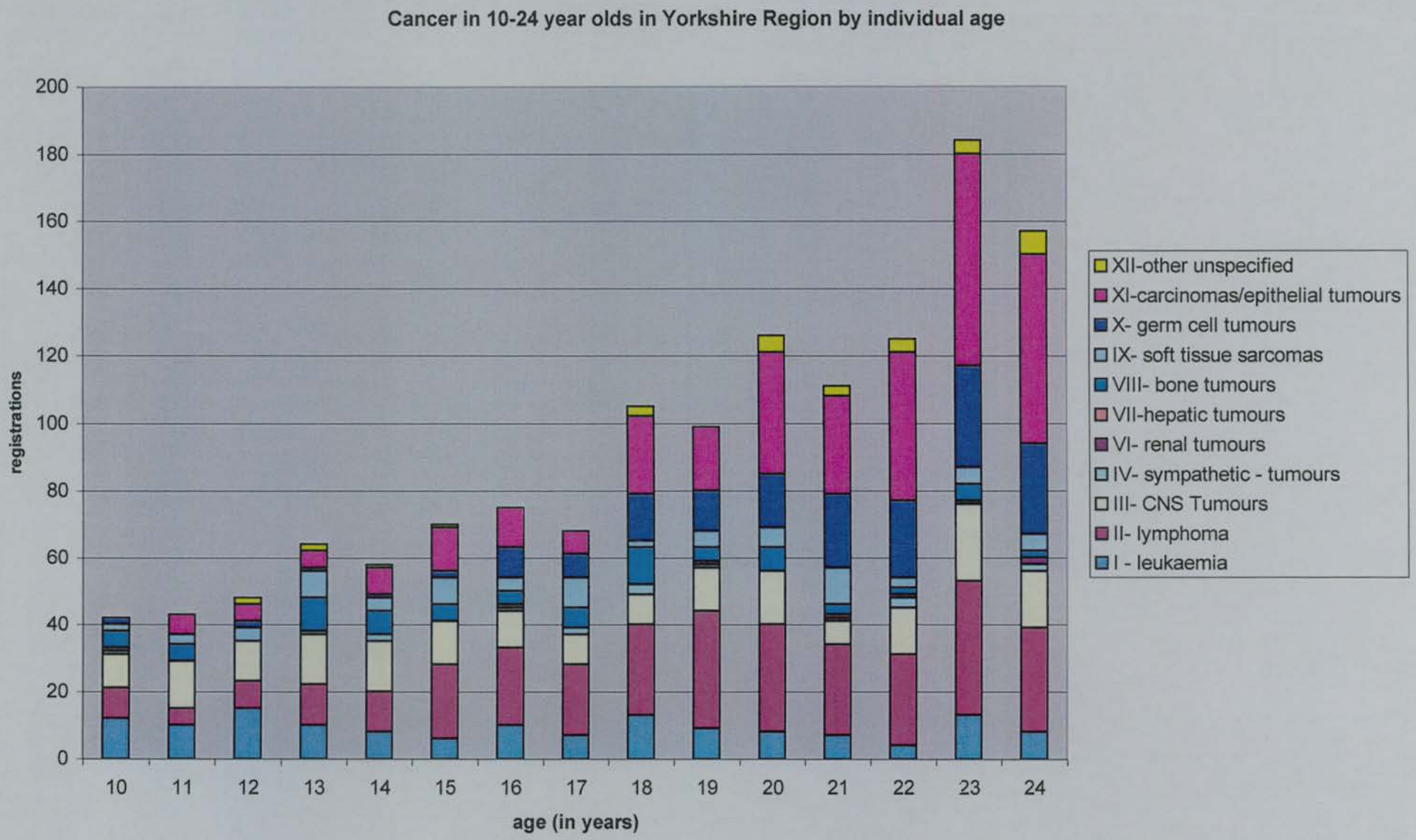

Cancer in 10-24 year olds in Yorkshire Region by individual age
registrations
200
180
160
140
120
100
80
60
40
20
0
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
age (in years)
XII-other unspecified
XI-carcinomas/epithelial tumours
X- germ cell tumours
IX- soft tissue sarcomas
VIII- bone tumours
VII-hepatic tumours
VI- renal tumours
IV- sympathetic - tumours
III- CNS Tumours
II- lymphoma
I - leukaemia

Figure 7.12

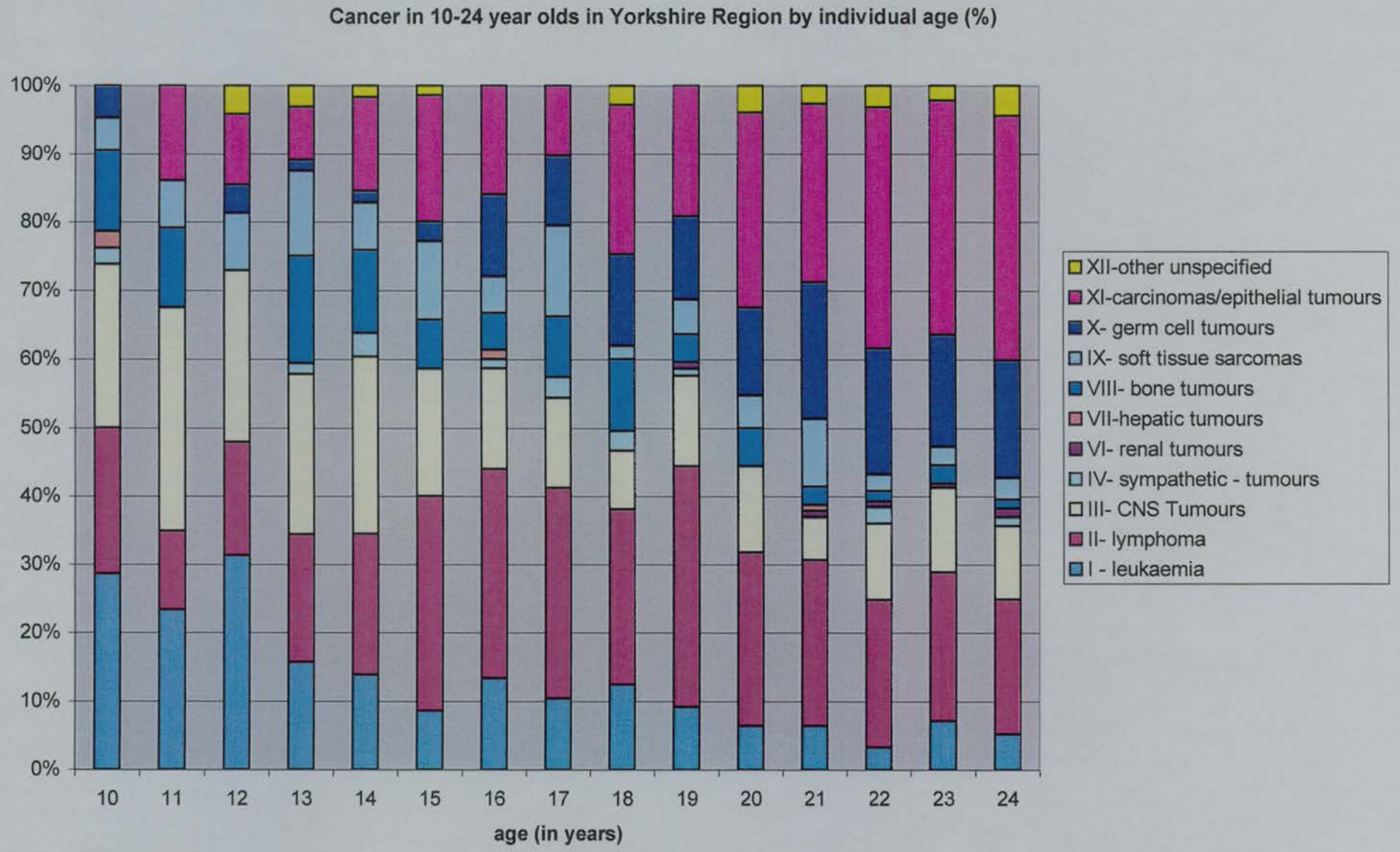

Cancer in 10-24 year olds in Yorkshire Region by individual age (%)
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
age (in years)
XII-other unspecified
XI-carcinomas/epithelial tumours
X- germ cell tumours
IX- soft tissue sarcomas
VIII- bone tumours
VII-hepatic tumours
VI- renal tumours
IV- sympathetic - tumours
III- CNS Tumours
II- lymphoma
I - leukaemia

Table 7.4 Number and Percentages of Malignancies by age - Northern and Yorkshire

Classification	10-14		15-19		20-24	
	n	%	n	%	N	%
I – leukaemia	99	22.4	98	13.1	72	5.9
II – lymphoma	79	17.9	211	28.2	292	23.9
III - CNS	107	24.3	98	13.1	135	11.1
IV – sympathetic tumours	8	1.8	11	1.5	11	0.9
V – retinoblastoma	0	0.0	0	0.0	0	0.0
VI - renal	1	0.2	4	0.5	10	0.8
VII – hepatic	1	0.2	2	0.3	1	0.1
VIII – bone	46	10.4	63	8.4	34	2.8
IX - soft tissue sarcoma	34	7.7	52	6.9	52	4.3
X - germ cell	14	3.2	77	10.3	220	18.0
XI – epithelial	47	10.7	127	17.0	368	30.2
XII – other	5	1.1	6	0.8	25	2.0
Total	441	100.0	749	100.0	1220	100.0

Table 7.5 Number and Percentages of Malignancies by age - Northern

Classification	10-14		15-19		20-24	
	n	%	n	%	N	%
I – leukaemia	44	23.7	53	16.0	32	6.2
II – lymphoma	33	17.7	83	25.0	135	26.1
III - CNS	41	22.0	43	13.0	58	11.2
IV – sympathetic tumours	4	2.2	4	1.2	6	1.2
V – retinoblastoma	0	0.0	0	0.0	0	0.0
VI - renal	1	0.5	3	0.9	5	1.0
VII – hepatic	0	0.0	1	0.3	0	0.0
VIII – bone	19	10.2	33	9.9	15	2.9
IX - soft tissue sarcoma	13	7.0	24	7.2	22	4.3
X - germ cell	8	4.3	33	9.9	102	19.7
XI – epithelial	23	12.4	53	16.0	140	27.1
XII – other	0	0.0	2	0.6	2	0.4
Total	186	100.0	332	100.0	517	100.0

Table 7.6 Number and Percentages of Malignancies by age - Yorkshire

Classification	10-14		15-19		20-24	
	n	%	n	%	N	%
I – leukaemia	55	21.6	45	10.8	40	5.7
II – lymphoma	46	18.0	128	30.7	157	22.3
III - CNS	66	25.9	55	13.2	77	11.0
IV – sympathetic tumours	4	1.6	7	1.7	5	0.7
V – retinoblastoma	0	0.0	0	0.0	0	0.0
VI - renal	0	0.0	1	0.2	5	0.7
VII – hepatic	1	0.4	1	0.2	1	0.1
VIII – bone	27	10.6	30	7.2	19	2.7
IX - soft tissue sarcoma	21	8.2	28	6.7	30	4.3
X - germ cell	6	2.4	44	10.6	118	16.8
XI – epithelial	24	9.4	74	17.7	228	32.4
XII – other	5	2.0	4	1.0	23	3.3
Total	255	100.0	417	100.0	703	100.0

The patterns of malignancy in the Northern and Yorkshire Region are remarkably similar. The increase in incidence of epithelial tumours with age is particularly noticeable in females and is mainly due to thyroid, skin (melanoma), breast, and cervix. A more detailed breakdown of these cancers is shown in tables 7.8 and 7.9. and figures 7.13 and 7.14

Germ cell tumours increase with age and include mainly testicular and ovarian tumours. The data show a decreasing incidence of CNS tumours and leukaemias with age in contrast to a rise in incidence of lymphomas with age group.

Table 7.7 Three commonest malignancies in each age group (using childhood classification)

Age group	Sex	Malignancy		
10-14	M	CNS (25.2%)	Lymphoma (22.0%)	Leukaemia (20.3%)
	F	Leukaemia (25.1%)	CNS (22.6%)	Lymphoma (12.8%)
15-19	M	Lymphoma (30.46%)	Leukaemia (14.2%)	CNS (12.5%)
	F	Lymphoma (25.8%)	Epithelial (23.3%)	CNS (13.5%)
20-24	M	Germ Cell (29.8%)	Lymphoma (25.1%)	Epithelial (15.8%)
	F	Epithelial (43.8%)	Lymphoma (22.5%)	CNS (9.2%)

Figure 7.13

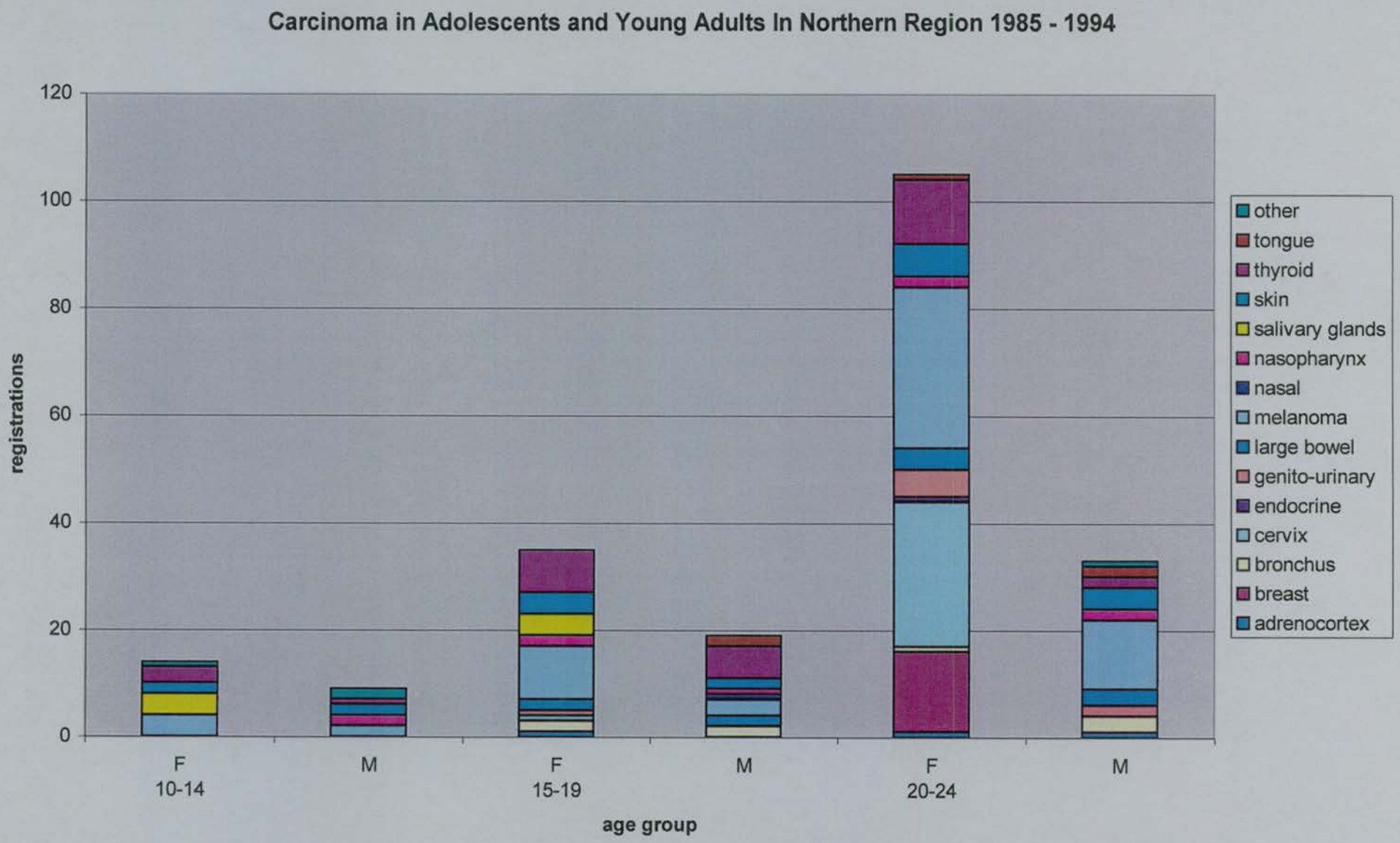
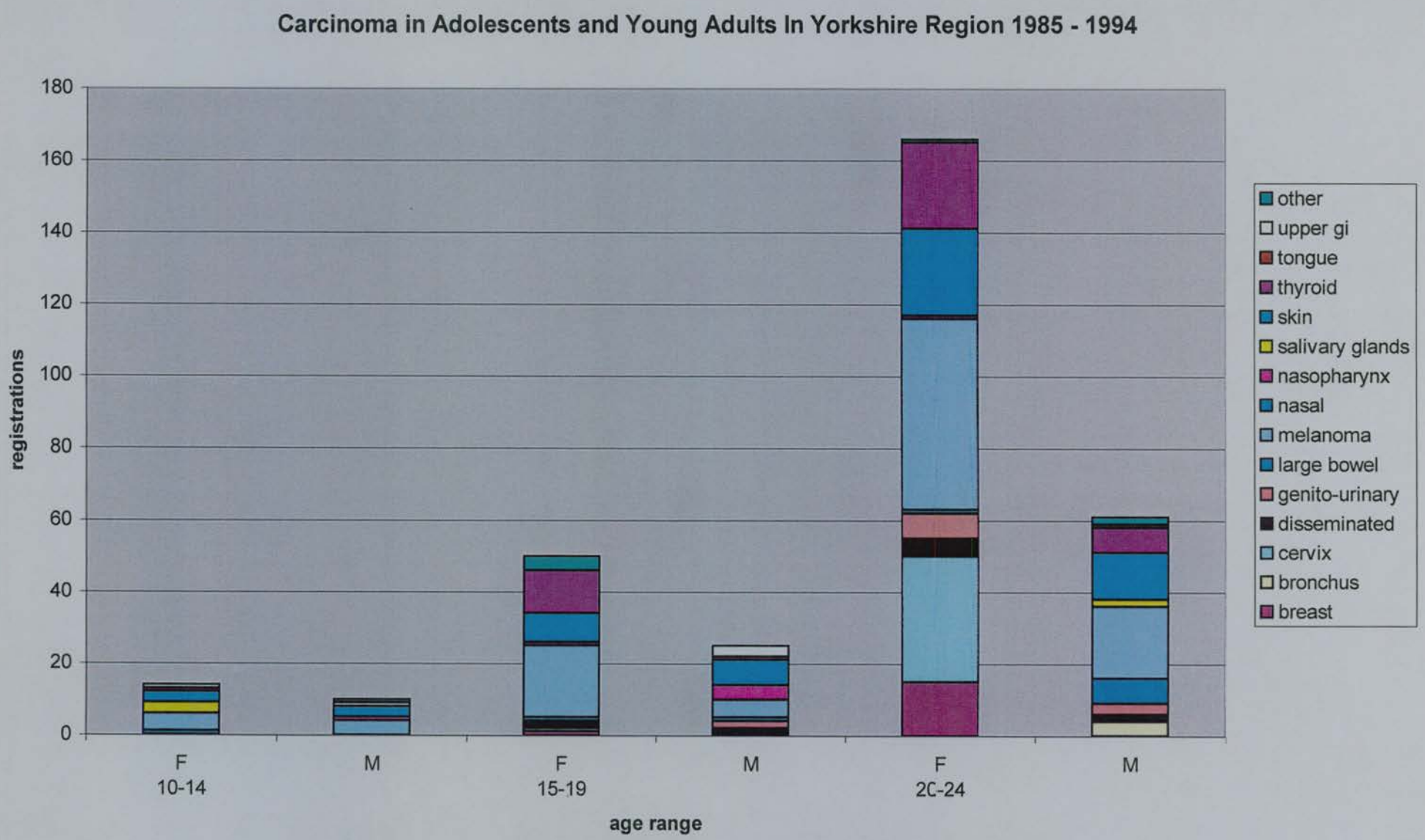

Carcinoma in Adolescents and Young Adults In Northern Region 1985 - 1994
registrations
120
100
80
60
40
20
0
F
10-14
M
F
15-19
M
F
20-24
M
age group
other
tongue
thyroid
skin
salivary glands
nasopharynx
nasal
melanoma
large bowel
genito-urinary
endocrine
cervix
bronchus
breast
adrenocortex

Figure 7.14


Carcinoma in Adolescents and Young Adults In Yorkshire Region 1985 - 1994
registrations
180
160
140
120
100
80
60
40
20
0
F
10-14
M
F
15-19
M
F
20-24
M
age range
other
upper gi
tongue
thyroid
skin
salivary glands
nasopharynx
nasal
melanoma
large bowel
genito-urinary
disseminated
cervix
bronchus
breast

The pattern of cancer in each of the selected age-sex bands demonstrably differs and is further summarised in table 7.7. This shows a predominance of CNS tumours in boys aged 10 - 14. In the same age group girls are much more likely to be affected by the Leukaemias. As the age increases lymphomas are the predominant malignancy in both male and female in young people aged 15 - 19. By the age of 20 - 24 germ cell malignancies in males have become dominant, closely followed by the lymphomas, particularly Hodgkin's Disease. However, the dominant malignancy at that age is found in epithelial cancers, particularly breast cancers in women. Hodgkin's Disease dominates the lymphoma group. In males aged 20 - 24 the majority of germ cell tumours are caused by testicular cancer.

Bone tumours, leukaemias, lymphomas, Hodgkin's Disease, germ cell tumours, CNS tumours, carcinoma epithelial tumours: in total account for 96.5% of all cancers (2326 during study period).

If one excludes the 20 - 24 year old age group the number of new malignancies in the 10 - 19 year old group amounts to 1281 during the study period, making an average of around 128 per year.

Table 7.8 Numbers of carcinomas and other epithelial tumours in adolescents in Northern Region (1985-1994)

	10-14		15-19		20-24		all	all
	F	M	F	M	F	M	F	M
adrenocortex			1		1	1	2	1
breast					15	0	15	0
bronchus			2	2	1	3	3	5
cervix			1		27	0	28	0
endocrine					1	0	1	0
genito-urinary			1		5	2	6	2
large bowel	0	0	2	2	4	3	6	5
melanoma	4	2	10	3	30	13	44	18
nasal				1	0	0	0	1
nasopharynx	0	2	2	1	2	2	4	5
salivary glands	4	0	4		0	0	8	0
skin	2	2	4	2	6	4	12	8
thyroid	3	1	8	6	12	2	23	9
tongue				2	1	2	1	4
other	1	2			0	1	1	3
total	14	9	35	19	105	33	154	61

Table 7.9 Numbers of carcinomas and other epithelial tumours in adolescents in Yorkshire Region (1985-1994)

	10-14		15-19		20-24		all	all
	F	M	F	M	F	M	F	M
breast			1		15	0	16	0
bronchus					0	4	0	4
cervix			1		35	0	36	0
disseminated			2	2	5	2	7	4
genito-urinary				2	7	3	7	5
large bowel	1	0	1	1	1	7	3	8
melanoma	5	4	20	5	53	20	78	29
nasal					0	0	0	0
nasopharynx		1	1	4	1	0	2	5
salivary glands	3				0	2	3	2
skin	3	3	8	7	24	13	35	23
thyroid	1		12	1	24	7	37	8
tongue					0	1	0	1
upper gi	1	1	0	3	0	0	1	4
other	0	1	4		1	2	5	3
total	14	10	50	25	166	61	230	96

The pattern of malignant melanoma seen in the Northern data is repeated in the Yorkshire data. The number of melanomas in the Yorkshire series is higher (or lower in the Northern dataset) than would be expected if similar incidence rates applied in both of the former regions, but this could be explained by the different sources of data being used, implying possibly that the cancer registry data is a more reliable source of non traditional children's tumours than the specialist register in the former Northern Region.

Tables 7.10 and 7.11 show the complete data set by ICCC code and age.

For more detailed analysis, a number of categories are now considered, and some smaller categories not considered further (retinoblastoma, renal, hepatic, sympathetic nervous system and other tumours), table 7.12

Table 7.12 Number of Malignancies recorded in each group 1985-1994 by age group

Age-band	Sex	Bone	Leukaemia	Lymphoma (NHL)	Hodgkin's	Germ cell	CNS	Sarcoma (soft tissue)	Epithelial	All
10-14	M	31	50	21	29	4	62	18	19	246
10-14	F	16	49	12	11	10	44	16	28	195
15-19	M	32	58	44	76	50	53	27	44	394
15-19	F	31	40	17	74	25	48	25	83	356
20-24	M	22	38	35	109	179	75	28	95	601
20-24	F	14	39	26	112	39	57	25	271	619
10-24	M	85	146	90	214	233	190	73	158	1241
10-24	F	61	128	55	197	74	149	66	382	1170
10-24	M&F	146	274	145	411	307	339	139	540	2411

Care must be used in interpreting differences between leukaemias and lymphomas, as in some instances the diagnostic differences between the two diseases can be difficult to distinguish form a pathological point of view.

Table 7.10

Numbers of Cancers in Young People in Northern Region by age and ICCC Code1985 - 1994

ICCC Classification	10	11	12	13	14	10-14 totals	15	16	17	18	19	15-19 totals	20	21	22	23	24	20-24 totals	Grand Totals
Ia lymphoid leukaemia	8	4	8	6	9	35	6	7	5	7	4	29	6	1	3	1	2	13	77
Ib acute non-lymphocytic leukaemia	0	1	1	4	1	7	4	5	2	7	1	19	4	1	0	3	3	11	37
Ic chronic myeloid leukaemia	0	1	0			1		2	0	1	1	4	3	0	4	0		7	12
Id Other specified leukaemias						0		1				1		0				0	1
Ie unspecified leukaemia	0	1				1						0					1	1	2
I - leukaemia	**8**	**7**	**9**	**10**	**10**	**44**	**10**	**15**	**7**	**15**	**6**	**53**	**13**	**2**	**7**	**4**	**6**	**32**	**129**
IIa Hodgkin's Disease	5	4	1	3	6	19	3	7	13	20	18	61	19	18	22	11	27	97	177
IIb Non Hodgkin lymphoma	2	3	3	3	1	12	4	4	3	6	5	22	8	1	4	11	6	30	64
IIc Burkitt's lymphoma			1			1						0		1	1	0	1	3	4
IId misc lymphoreticular neoplams						0						0						0	0
IIe Unspecifed lymphomas				1		1						0	1			1	3	5	6
II- lymphoma	**7**	**7**	**5**	**7**	**7**	**33**	**7**	**11**	**16**	**26**	**23**	**83**	**28**	**20**	**27**	**23**	**37**	**135**	**251**
IIIa Ependymoma	1	1	0	1	1	4	1	0	2	0		3	1	0	1	3	0	5	12
IIIb Astrocytoma	7	4	4	5	2	22	3	4	3	2	1	13	0	3	5	3	5	16	51
IIIc Primitive neuro ectodermal tumours	1	1	0	0	1	3	0				1	1	1	1	0	1		3	7
IIId Other gliomas		0	0	1	1	2	1	1	1	3	0	6	1	4	0	1	3	9	17
IIIe Other specified intracranial/spinal	1	1	2	0	1	5	3	1	2	2	2	10	1	1	4	0	1	7	22
IIIf Unspecified intracranial/spinal	1	1	2	0	1	5	3	3	2	0	2	10	6	1	3	4	4	18	33
III- CNS Tumours	**11**	**8**	**8**	**7**	**7**	**41**	**11**	**9**	**10**	**7**	**6**	**43**	**10**	**10**	**13**	**12**	**13**	**58**	**142**
IVa (Ganglio)neuroblastoma	1			2	0	3			2	1	0	3			0		0	0	6
IVb Other sympathetic system tumours				1	0	1		0	0	0	1	1	2	0	1	2	1	6	8
IV- sympathetic - tumours	**1**	**0**	**0**	**3**	**0**	**4**	**0**	**0**	**2**	**1**	**1**	**4**	**2**	**0**	**1**	**2**	**1**	**6**	**14**
Va Wilm's tumours					1	1	1			1		2	1		0			1	4
Vb Renal carcinoma						0			1		0	1	1	0	1	1	1	4	5
VI- renal tumours	**0**	**0**	**0**	**0**	**1**	**1**	**1**	**0**	**1**	**1**	**0**	**3**	**2**	**0**	**1**	**1**	**1**	**5**	**9**
VIIb Hepatic carcinoma	0					0		1				1						0	1
VII-hepatic tumours	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**1**	**0**	**0**	**0**	**1**	**0**	**0**	**0**	**0**	**0**	**0**	**1**
VIIIa Osteosarcoma		2	1	1	2	6	1	2	6	2	5	16	3	1	2	1	0	7	29
VIIIb Chondrosarcoma	0					0		1	0	1		2			1	0	0	1	3
VIIIc Ewing's sarcoma	2	1	3	2	1	9	0	5	1	3	2	11	1	0	2	1	1	5	25
VIIId Other specified bone tumours	1	1				2		2		0		2				1	1	2	6
VIIIe Unspecified bone tumours	2					2	1			1		2						0	4
VIII- bone tumours	**5**	**4**	**4**	**3**	**3**	**19**	**2**	**10**	**7**	**7**	**7**	**33**	**4**	**1**	**5**	**3**	**2**	**15**	**67**
IXa Rhabdomyosarcoma	2	0	1	0	1	4		2	4	4	0	10	2	1	1			4	18
IXb Fibrosarcomas		1	0	0	0	1	2	2	1	0	1	6	3	3	2	1	1	10	17
IXc Kaposi's sarcoma						0						0				0	0	0	0
IXd Other specified sarcomas	2	1	1	1	1	6	1	1	3	0	0	5	1	2	0	0	2	5	16
IXe Unspecified soft tissue sarcomas		1	0	0	1	2	1	0	1	1	0	3	2	0	1		0	3	8
IX- soft tissue sarcomas	**4**	**3**	**2**	**1**	**3**	**13**	**4**	**5**	**9**	**5**	**1**	**24**	**8**	**6**	**4**	**1**	**3**	**22**	**59**
Xa Intracranial/spinal germ cell tumours	1	1	1	1		4		1	0	0	0	1		0	1	0		1	6
Xb Other non-gonadal germ cell tumours					1	1	0	1	1	0	2	4	1	3	3	1	3	11	16
Xc Gonadal germ cell tumours			0	2	1	3	1	5	1	3	9	19	7	13	10	22	23	75	97
Xd Gonadal carcinomas						0	1	1	3	1	3	9	2	3	4	3	1	13	22
Xe Other unspecified gonadal tumours						0						0			1		1	2	2
X- germ cell tumours	**1**	**1**	**1**	**3**	**2**	**8**	**2**	**8**	**5**	**4**	**14**	**33**	**10**	**19**	**19**	**26**	**28**	**102**	**143**
XIa - Adrenocortical carcinomas						0		1				1			1	3	0	4	5
XIb Thyroid carcinomas	1	0	1	0	2	4	3	0	3	3	5	14	3	0	5	2	4	14	32
XIc Nasopharyngeal carcinomas			1	0	1	2	1	0	1	1	0	3	2	1	0	1	0	4	9
XId Malignant melanoma			2	3	1	6	3	5	0	3	2	13	9	5	12	7	10	43	62
XIe Skin carcinoma	0	1	0	2	1	4	2	1	0	3	0	6	1	1	0	3	5	10	20
XIf Other unspecified carcinomas	1	1	1	2	2	7	1	4	4	5	3	17	4	8	10	16	27	65	89
XI-carcinomas/epithelial tumours	**2**	**2**	**5**	**7**	**7**	**23**	**10**	**11**	**8**	**15**	**10**	**53**	**19**	**15**	**28**	**32**	**46**	**140**	**216**
XIIa Other specified malignant tumours				0		0	0			0	1	1	0	0	2	0	0	2	3
XIIb Other unspecified malignant tumours			0	0	0	0				1		1	0	0	0	0	0	0	1
XII-other unspecified	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**1**	**1**	**2**	**0**	**0**	**2**	**0**	**0**	**2**	**4**
Grand Total	**39**	**32**	**34**	**41**	**40**	**186**	**47**	**70**	**65**	**82**	**69**	**333**	**96**	**73**	**107**	**104**	**137**	**517**	**1036**

Table 7.11

Cancer in Young People in Yorkshire by age and ICCC Code 1985 - 1994

ICCC Classification	10	11	12	13	14	10-14 totals	15	16	17	18	19	15-19 totals	20	21	22	23	24	20-24 totals	Grand Totals
Ia lymphoid leukaemia	8	8	8	9	5	38	3	8	4	11	6	32	2	2	3	2	2	11	81
Ib acute non-lymphocytic leukaemia	2	2	6	1	2	13	3	1	2	2	3	11	3	4		10	6	23	47
Ic chronic myeloid leukaemia	2		1		1	4		1	1			2	2	1	1	1		5	11
Ie unspecified leukaemia						0						0	1					1	1
I - leukaemia	**12**	**10**	**15**	**10**	**8**	**55**	**6**	**10**	**7**	**13**	**9**	**45**	**8**	**7**	**4**	**13**	**8**	**40**	**140**
IIa Hodgkin's Disease	4	2	3	5	7	21	10	14	14	22	28	88	25	23	20	35	23	126	235
IIb Non Hodgkin lymphoma	3	3	3	7	5	21	12	9	7	4	7	39	7	4	7	5	8	31	91
IIc Burkitt's lymphoma			1			1						0						0	1
IId misc lymphoreticular neoplams						0				1		1						0	1
IIe Unspecified lymphoma	2		1			3						0						0	3
II- lymphoma	**9**	**5**	**8**	**12**	**12**	**46**	**22**	**23**	**21**	**27**	**35**	**128**	**32**	**27**	**27**	**40**	**31**	**157**	**331**
IIIa Ependymoma	1		2	1	1	5		1		2		3	2	1		1	1	5	13
IIIb Astrocytoma	4	6	5	6	6	27	6	6	4	1	2	19	6	2	5	8	7	28	74
IIIc Primitive neuro ectodermal tumours	3	1	1	4	1	10	2				3	5			1	2		3	18
IIId Other gliomas		1	1		1	3		1	1	3	1	6	1		3	1	2	7	16
IIIe Other specified intracranial/spinal	1	1	1	1	2	6						0	1		1	1		3	9
IIIf Unspecified intracranial/spinal	1	5	2	3	4	15	5	3	4	3	7	22	6	4	4	10	7	31	68
III- CNS Tumours	**10**	**14**	**12**	**15**	**15**	**66**	**13**	**11**	**9**	**9**	**13**	**55**	**16**	**7**	**14**	**23**	**17**	**77**	**198**
IVa (Ganglio)neuroblastoma	1				1	2			1	1	1	3			2		1	3	8
IVb Other sympathetic system tumours				1	1	2		1	1	2		4			1		1	2	8
IV- sympathetic - tumours	**1**	**0**	**0**	**1**	**2**	**4**	**0**	**1**	**2**	**3**	**1**	**7**	**0**	**0**	**3**	**0**	**2**	**5**	**16**
Va Wilm's tumours						0						0			1			1	1
Vb Renal carcinoma						0					1	1		1		1	2	4	5
VI- renal tumours	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**0**	**1**	**1**	**0**	**1**	**1**	**1**	**2**	**5**	**6**
VIIb Hepatic carcinoma	1					1		1				1		1				1	3
VII-hepatic tumours	**1**	**0**	**0**	**0**	**0**	**1**	**0**	**1**	**0**	**0**	**0**	**1**	**0**	**1**	**0**	**0**	**0**	**1**	**3**
VIIIa Osteosarcoma		4		5	6	15	4	2	3	7	4	20	5	2	1	2		10	45
VIIIb Chondrosarcoma						0		2	1	2		5			1	1	1	3	8
VIIIc Ewing's sarcoma	3	1		4	1	9			2	2		4	2	1		1	1	5	18
VIIId Other specified bone tumours	1					1	1					1				1		1	3
VIIIe Unspecified bone tumours	1			1		2						0						0	2
VIII- bone tumours	**5**	**5**	**0**	**10**	**7**	**27**	**5**	**4**	**6**	**11**	**4**	**30**	**7**	**3**	**2**	**5**	**2**	**19**	**76**
IXa Rhabdomyosarcomas		2		5		7		1	1			2	1	1				2	11
IXb Fibrosarcomas		1	3	1	1	6	5		6	1	1	13		4	3	2	1	10	29
IXc Kaposi's sarcoma						0						0				1	1	2	2
IXd Other specified sarcomas	1			2	2	5		2	2		3	7	4	4		2	2	12	24
IXe Unspecified soft tissue sarcomas	1		1		1	3	3	1		1	1	6	1	2			1	4	13
IX- soft tissue sarcomas	**2**	**3**	**4**	**8**	**4**	**21**	**8**	**4**	**9**	**2**	**5**	**28**	**6**	**11**	**3**	**5**	**5**	**30**	**79**
Xa Intracranial/spinal germ cell tumours						0		1	1	1		3		1		1		2	5
Xb Other non-gonadal germ cell tumours						0		2	1	1	2	6			3	1		4	10
Xc Gonadal germ cell tumours	2		2	1	1	6	2	6	4	10	10	32	15	20	17	25	25	102	140
Xd Gonadal carcinomas						0			1	1		2	1	1	3	2	2	9	11
Xe Other unspecified gonadal tumours						0				1		1				1		1	2
X- germ cell tumours	**2**	**0**	**2**	**1**	**1**	**6**	**2**	**9**	**7**	**14**	**12**	**44**	**16**	**22**	**23**	**30**	**27**	**118**	**168**
XIb Thyroid carcinomas					1	1	4	2		3	4	13	9	4	5	8	5	31	45
XIc Nasopharyngeal carcinomas					1	1	1	1	1		2	5	1					1	7
XId Malignant melanoma		2	2		5	9	3	2	2	7	11	25	11	12	14	24	12	73	107
XIe Skin carcinoma		2	1	2	1	6	3	1	3	7	1	15	6	5	9	7	10	37	58
XIf Other unspecified carcinomas		2	2	3		7	2	6	1	6	1	16	9	8	16	24	29	86	109
XI-carcinomas/epithelial tumours	**0**	**6**	**5**	**5**	**8**	**24**	**13**	**12**	**7**	**23**	**19**	**74**	**36**	**29**	**44**	**63**	**56**	**228**	**326**
XIIa Other specified malignant tumours				1		1	1			2		3	4	2	4	4	6	20	24
XIIb Other unspecified malignant tumours			2	1	1	4				1		1	1	1			1	3	8
XII-other unspecified	**0**	**0**	**2**	**2**	**1**	**5**	**1**	**0**	**0**	**3**	**0**	**4**	**5**	**3**	**4**	**4**	**7**	**23**	**32**
Grand Total	**42**	**43**	**48**	**64**	**58**	**255**	**70**	**75**	**68**	**105**	**99**	**417**	**126**	**111**	**125**	**184**	**157**	**703**	**1375**

7.3 Incidence Rates of cancer by county in Northern and Yorkshire

Data are now presented, broken down by county in the Northern and Yorkshire Region. Table 7.13 shows the crude data showing actual number of malignancies and the % distribution by county. In terms of pure numbers (which clearly has a bearing on workload), West Yorkshire contributes more to the data series than any other county in the region, with the smallest contribution coming from Northumberland.

Table 7.13 (a) Number of Malignancies recorded in each county 1985-1994

County	Bone	Leukaemia	NHL
East Yorkshire	18	33	22
North Yorkshire	15	27	21
West Yorkshire	43	80	53
Tyneside	17	42	34
Cleveland	19	24	13
Northumberland	7	12	5
Cumbria	15	17	9
County Durham	9	34	13
Total	143	269	170

Table 7.13 (b) Number of Malignancies recorded in each county 1985-1994

County	Hodgkin's	Germ cell	CNS
East Yorkshire	58	46	49
North Yorkshire	37	23	36
West Yorkshire	139	99	113
Tyneside	66	65	58
Cleveland	35	27	26
Northumberland	10	12	8
Cumbria	33	21	23
County Durham	33	18	27
Total	411	311	340

Table 7.13 (c) Number of Malignancies recorded in each county 1985-1994

County	Sarcoma	Epithelial	All
East Yorkshire	18	85	342
North Yorkshire	15	63	250
West Yorkshire	46	178	783
Tyneside	16	89	397
Cleveland	18	49	216
Northumberland	11	14	81
Cumbria	7	31	161
County Durham	7	34	181
Total	138	543	2411

Table 7.14 Age & Sex Standardised Incidence Rates (person years) [ASRs] of Malignancies recorded in each region 1985-1994 per million population for 10-24 year age group

Region	Northern		Yorkshire	
	ASR	*95% CL*	*ASR*	*95% CL*
Bone	11.3	8.7-14.0	10.5	8.1-12.8
Leukaemia	21.7	18.0-25.3	19.3	16.1-22.5
Lymphoma	40.4	35.4-45.4	45.54	40.6-50.4
Hodgkin's	28.5	24.3-32.7	32.3	28.2-36.4
Germ Cell	22.5	18.7-26.2	23.2	19.7-26.7
CNS	22.8	19.8-26.6	27.3	23.5-31.3
Sarcoma	9.8	7.2-12.2	10.9	8.5-13.3
Epithelial*	34.6	30.0-39.2	45.0	40.1-49.8
All tumours*	167.5	157.3-177.7	189.8	179.7-199.8

*$p<0.05$

Table 7.14 shows age sex standardised rates for the region and shows an overall significant difference between all tumours in the Northern Region compared to Yorkshire. Significant differences are seen in the rates for epithelial tumours. CNS tumours in the Northern region are also lower than might be expected and could be due to ascertainment problems rather than necessarily being a real difference.

Table 7.15 Age & Sex Standardised Rates (person years) [ASR's] of Malignancies recorded in each county 1985-1994 per million population for 10-24 year age group

Bone tumours

County/Region	ASR	95%CL
East Yorkshire	10.6	5.6-15.4
North Yorkshire	11.2	5.5-16.9
West Yorkshire	10.3	7.3-13.4
Tyneside	7.4	3.9-10.9
Cleveland	16.1	8.9-23.4
Northumberland	12.0	3.1-21.0
Cumbria	15.8	7.8-23.8
County Durham	7.5	2.6-12.3
Yorkshire	10.5	8.1-12.8
Northern	10.3	8.7-14.0

Leukaemias

County/Region	ASR	95%CL
East Yorkshire	19.1	12.6-25.6
North Yorkshire	19.9	12.4-27.4
West Yorkshire	19.3	15.0-23.5
Tyneside	18.4	12.8-24.0
Cleveland	20.4	12.3-28.6
Northumberland	20.1	8.7-31.6
Cumbria	18.2	9.5-26.8
County Durham	28.1	18.7-37.6
Yorkshire	19.3	16.1-22.5
Northern	21.7	18.0-25.3

Lymphomas

County/Region	ASR	95%CL
East Yorkshire	47.6	37.2-58.1
North Yorkshire	42.8	31.8-53.8
West Yorkshire	45.8	39.3-52.2
Tyneside	42.3	34.0-50.6
Cleveland	41.8	30.0-53.6
Northumberland	27.6	13.6-41.7
Cumbria	45.6	31.8-59.4
County Durham	38.1	27.1-49.1
Yorkshire	45.5	40.6-50.4
Northern	40.4	35.4-45.4

Hodgkin's Disease

County/Region	ASR	95%CL
East Yorkshire	34.6	25.7-43.6
North Yorkshire	27.6	18.7-36.4
West Yorkshire	33.1	27.6-38.6
Tyneside	27.8	21.1-34.5
Cleveland	30.6	20.4-40.7
Northumberland	18.8	7.1-30.5
Cumbria	35.7	23.5-47.9
County Durham	27.3	18.0-36.6
Yorkshire	32.3	28.2-36.4
Northern	28.5	24.3-32.7

Germ Cell Tumours

County/Region	ASR	95%CL
East Yorkshire	28.0	19.7-36.0
North Yorkshire	17.0	10.0-24.0
West Yorkshire	23.4	18.8-28.0
Tyneside	27.2	20.6-33.9
Cleveland	24.2	15.1-33.3
Northumberland	22.4	9.7-35.2
Cumbria	23.2	13.3-33.2
County Durham	14.9	8.0-21.7
Yorkshire	23.2	19.7-26.7
Northern	22.5	18.7-26.2

CNS Tumours

County/Region	ASR	95%CL
East Yorkshire	28.6	20.6-36.7
North Yorkshire	26.9	18.1-35.8
West Yorkshire	27.0	22.0-31.8
Tyneside	25.0	18.6-31.5
Cleveland	22.4	13.8-31.1
Northumberland	14.0	4.2-23.8
Cumbria	24.8	14.7-34.9
County Durham	22.3	13.9-30.7
Yorkshire	27.3	23.5-31.3
Northern	22.8	19.8-26.6

Sarcomas

County/Region	ASR	95%CL
East Yorkshire	10.6	5.7-15.5
North Yorkshire	11.2	5.5-16.8
West Yorkshire	11.0	7.8-14.2
Tyneside	6.9	3.5-10.3
Cleveland	15.6	8.4-22.8
Northumberland	19.2	7.8-30.7
Cumbria	7.4	1.9-12.8
County Durham	5.8	1.5-10.1
Yorkshire	10.9	8.5-13.3
Northern	9.8	7.2-12.2

Epithelial Tumours

County/Region	ASR	95%CL
East Yorkshire	50.5	39.8-61.4
North Yorkshire	47.8	36.0-59.6
West Yorkshire	42.1	35.9-48.3
Tyneside	37.5	29.7-45.3
Cleveland	43.1	31.1-55.2
Northumberland	26.1	12.4-39.9
Cumbria	34.0	22.0-45.9
County Durham	28.1	18.7-37.6
Yorkshire	45.0	40.1-49.8
Northern	34.6	30.0-39.2

All Tumours

County/Region	ASR	95%CL
East Yorkshire	202.7	181.2-224.3
North Yorkshire	186.8	163.7-210.0
West Yorkshire	186.5	173.4-199.6
Tyneside	170.0	152.3-185.6
Cleveland	188.1	163.0-213.2
Northumberland	145.2	113.4-177.0
Cumbria	174.4	147.4-201.3
County Durham	149.7	127.9-171.5
Yorkshire	189.8	179.7-199.8
Northern	167.5	157.3-177.7

Table 7.15 shows age/sex standardised rates by county. There are some striking differences in the data between counties, although they do not reach statistical significance. The results for bone tumours in Tyneside and County Durham are surprisingly lower than might be expected. The reasons for this are unclear. Similarly some of the data for Northumberland in respect of Hodgkin's disease, CNS and epithelial tumours seem somewhat low and may represent some leakage to treatment centres in adjacent Scotland. Although arrangements do exist to transfer data between Scotland and England, such arrangements may not be as robust as capturing the data direct in the place of treatment.

Tables 7.16 and 7.17 show incidence rates for males and females.

Table 7.16 Incidence Rates in Males by Age Band per million person years

Cancer	Yorkshire			Northern		
	10-14	15-19	20-24	10-14	15-19	20-24
Bone	17.8	9.0	9.6	11.3	20.4	7.8
Leukaemia	24.0	20.5	15.5	23.6	32.1	14.8
NHL	13.3	23.0	12.6	6.1	15.5	15.6
Hodgkin's	13.3	32.9	46.5	14.3	35.0	40.0
Germ Cell	1.8	24.6	73.9	2.1	19.4	68.6
CNS	32.9	24.6	29.6	25.6	22.4	30.4
Sarcoma	9.8	13.1	14.0	7.2	10.7	7.8
Epithelial	8.9	20.5	45.1	9.2	18.5	29.5
All	127.8	172.5	249.0	104.4	178.8	229.4

Although similar in most age groups, the incidence of leukaemia in Yorkshire is lower than expected in 15-19 year age band and again this may be a real difference or could possibly be due to improved recording of data by a specialist tumour registry in the Northern region. Haematological malignancies are often poorly recorded by cancer registries (145).

There are also some observed differences between the reported incidence rates in the younger age groups in bone tumours, lower incidence in 10-14 year olds and higher incidence in 15-19 year group.

Table 7.17 Incidence Rates in Females by Age Band per million person years

Cancer	Yorkshire			Northern		
	10-14	15-19	20-24	10-14	15-19	20-24
Bone	6.6	16.3	4.5	9.7	12.3	7.1
Leukaemia	26.3	17.1	14.1	22.7	20.5	17.8
NHL	5.6	9.4	10.4	6.5	6.2	5.3
Hodgkin's	5.6	41.1	46.7	5.4	26.7	43.5
Germ Cell	3.7	12.0	13.4	6.5	11.3	18.6
CNS	27.2	21.4	27.4	16.2	23.6	17.8
Sarcoma	9.4	10.3	8.2	6.5	13.3	12.4
Epithelial	13.1	42.0	123.9	15.2	34.9	92.3
All	104.1	177.4	271.5	90.9	152.7	224.6

Table 7.18 Rate ratio of males to female cancer incidence

Cancer	Yorkshire			Northern		
	10-14	15-19	20-24	10-14	15-19	20-24
Bone	2.7	0.6	2.1	1.2	1.7	1.1
Leukaemia	0.9	1.2	1.1	1.0	1.6	0.8
NHL	2.4	2.4	1.2	0.9	2.5	2.9
Hodgkin's	2.4	0.8	1.0	2.6	1.3	0.9
Germ Cell	0.5	2.1	5.5	0.3	1.7	3.7
CNS	1.2	1.1	1.1	1.6	0.9	1.7
Sarcoma	1.0	1.3	1.7	1.1	0.8	0.6
Epithelial	0.7	0.5	0.4	0.6	0.5	0.3
All	1.2	1.0	0.9	1.1	1.2	1.0

Table 7.18 confirms the excess of cancer in young people seen in males, although the excess then changes to females in the 20-24 year age group. There is a large excess of germ cell tumours in males (reflecting the incidence of testicular cancer). Notable differences are also seen in bone tumours. Differences are also seen with a lower rate ratio of epithelial cancers, reflecting increased incidence of certain tumours e.g. thyroid and skin in females, together with the inclusion of some female specific tumours (breast, ovary and cervix)

7.4 Trends over time

7.4.1 Overall Trends

Trends over time have been plotted, looking at the number of individual cancers by year over the ten year period of study. These have been plotted for all cancers in figure 7.15. To eliminate fluctuations, three year rolling figures have been plotted and are shown in figure 7.16 (smoothing). The overall trend is downwards. Ideally, it would have been useful to plot age/sex standardised rates to take account of fluctuations in population size. However, this is not possible due to the absence of reliable population statistics for such small age groups apart from the very accurate figures available in census years (1981,1991, 2001).

7.4.2 Trends for individual cancers

Figures 7.17 and 7.18 show the trend data for individual cancers, unsmoothed and smoothed figures respectively. At the end of the ten year study period, the numbers of lymphoma had fallen. There are small, but perceptible rises in the number of epithelial and other tumours.

Figure 7.15

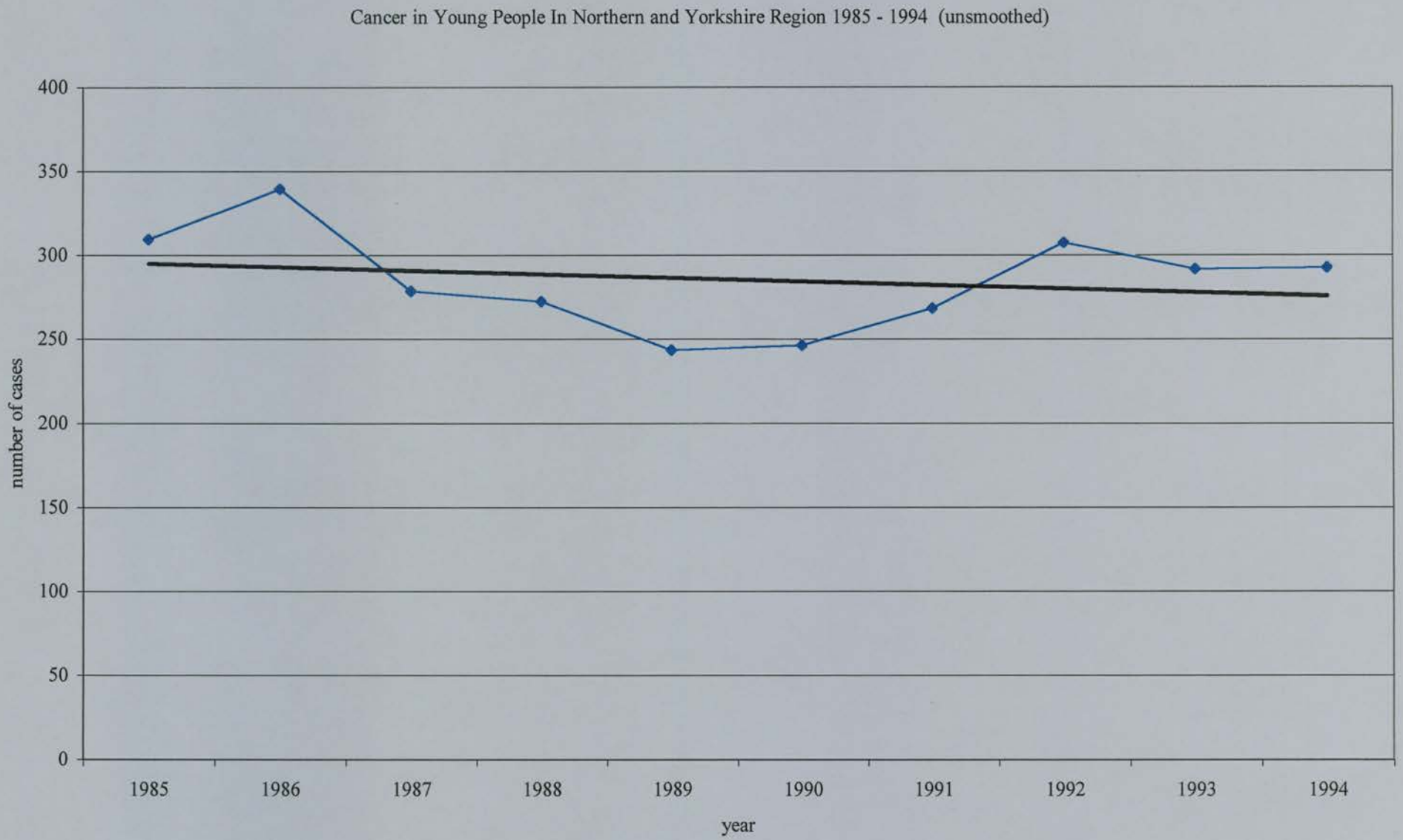

Cancer in Young People In Northern and Yorkshire Region 1985 - 1994 (unsmoothed)
400
350
300
250
200
150
100
50
0
number of cases
1985
1986
1987
1988
1989
1990
1991
1992
1993
1994
year

Figure 7.16


Cancer in Young People In Northern and Yorkshire Region 1985 - 1994 (smoothed)
350
300
250
200
150
100
50
0
number of cases
1986
1987
1988
1989
1990
1991
1992
1993
year

Figure 7.17

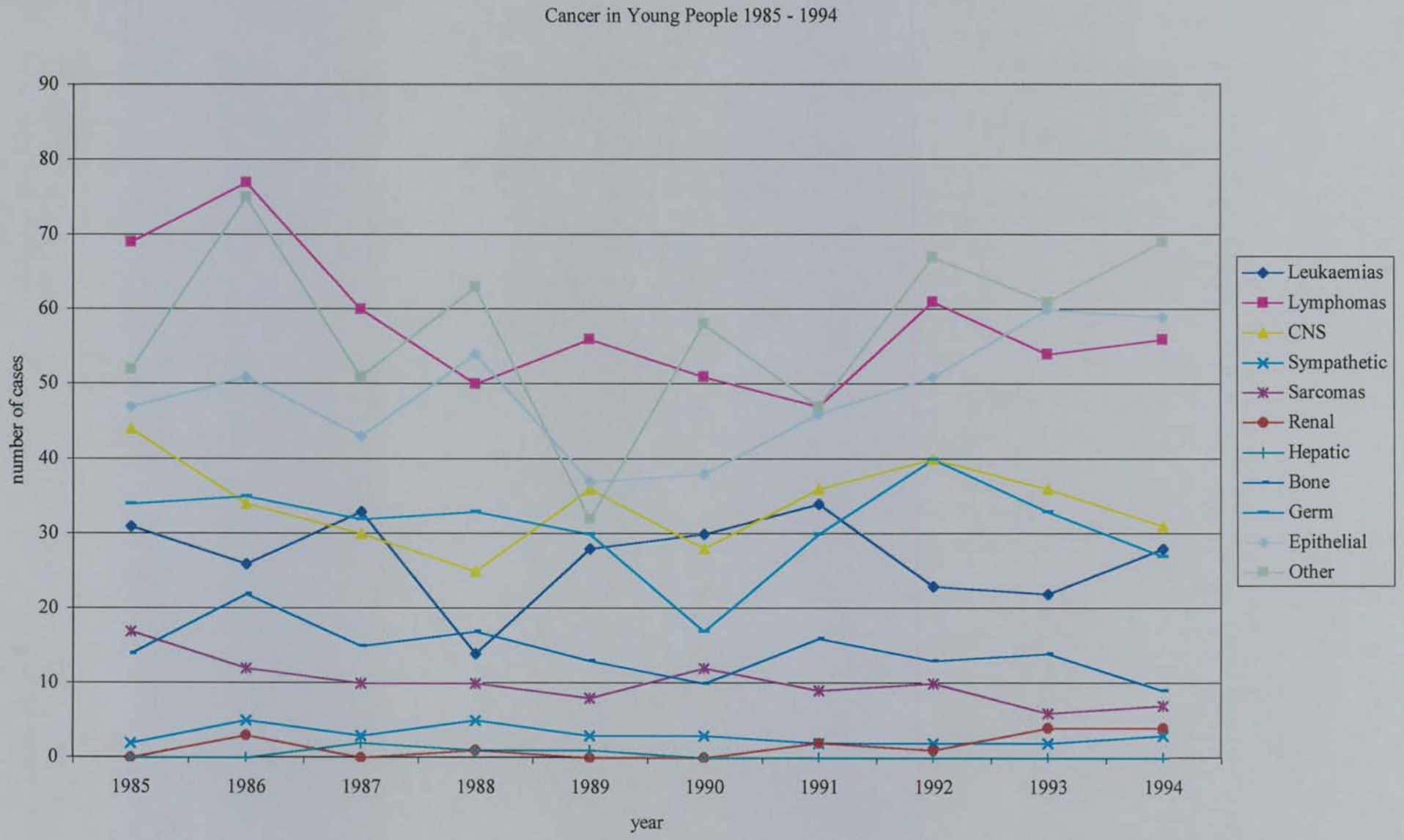
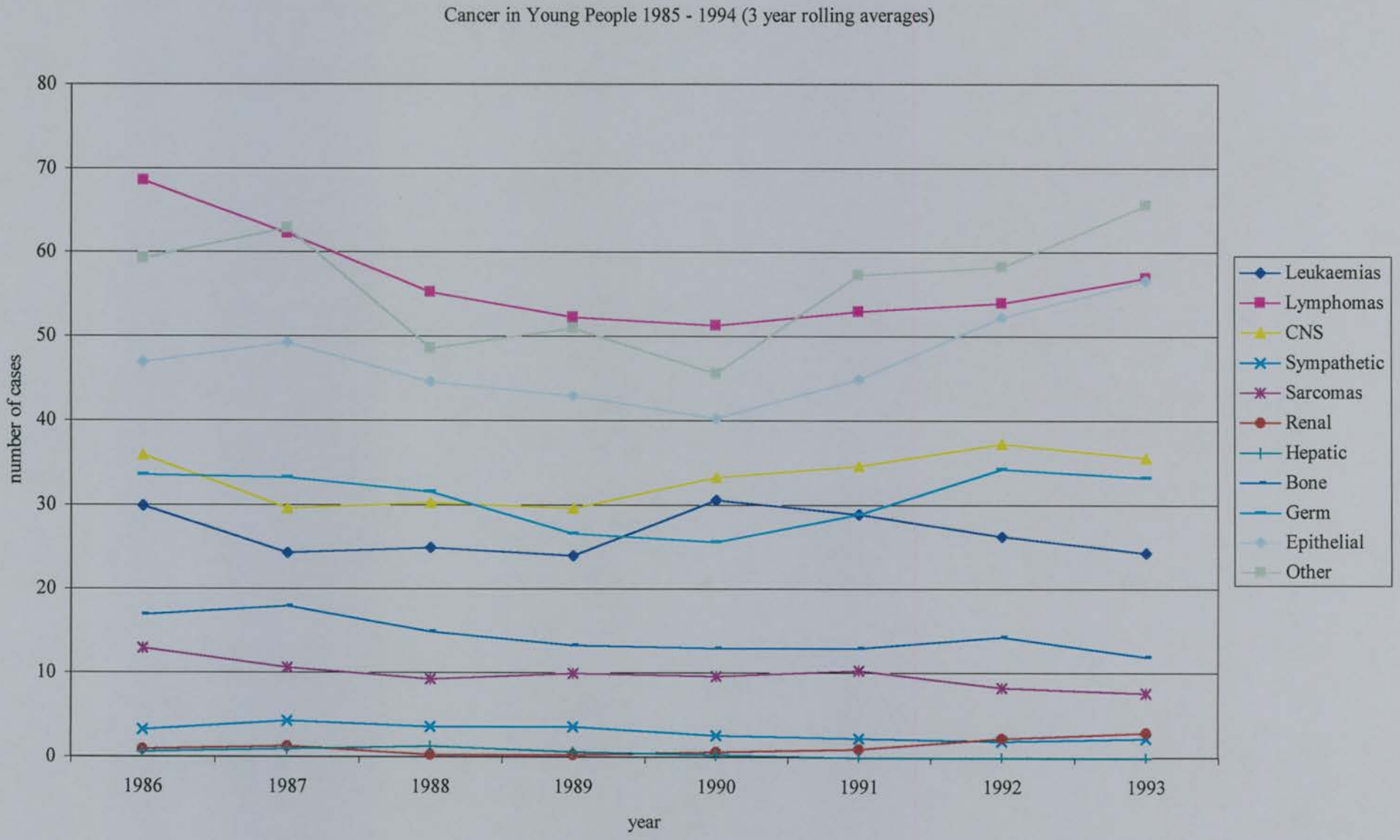

Cancer in Young People 1985 - 1994
number of cases
90
80
70
60
50
40
30
20
10
0
1985
1986
1987
1988
1989
1990
1991
1992
1993
1994
year
Leukaemias
Lymphomas
CNS
Sympathetic
Sarcomas
Renal
Hepatic
Bone
Germ
Epithelial
Other

Figure 7.18


Cancer in Young People 1985 - 1994 (3 year rolling averages)
number of cases
80
70
60
50
40
30
20
10
0
1986
1987
1988
1989
1990
1991
1992
1993
year
Leukaemias
Lymphomas
CNS
Sympathetic
Sarcomas
Renal
Hepatic
Bone
Germ
Epithelial
Other

7.5 Survival

Survival results are shown in two ways. Firstly survival curves are shown. Survival has also been examined using Cox's proportional hazard ratio technique (this was fully described in section 6.8)

Firstly survival curves figures 7.19 -7.23 will be considered.

7.5.1 Overall Five Year Survival

Overall survival is shown in figure 7.19

In this series, over 28.1% of young people diagnosed with cancer had died during the ten year period and up to the time of follow up (2 years after the end of the ten-year period). There were a total of 387 deaths during this period from malignant causes (table 7.19).

Table 7.19 Analysis of deaths and 5 year survival rate by disease category (ICCC Category)

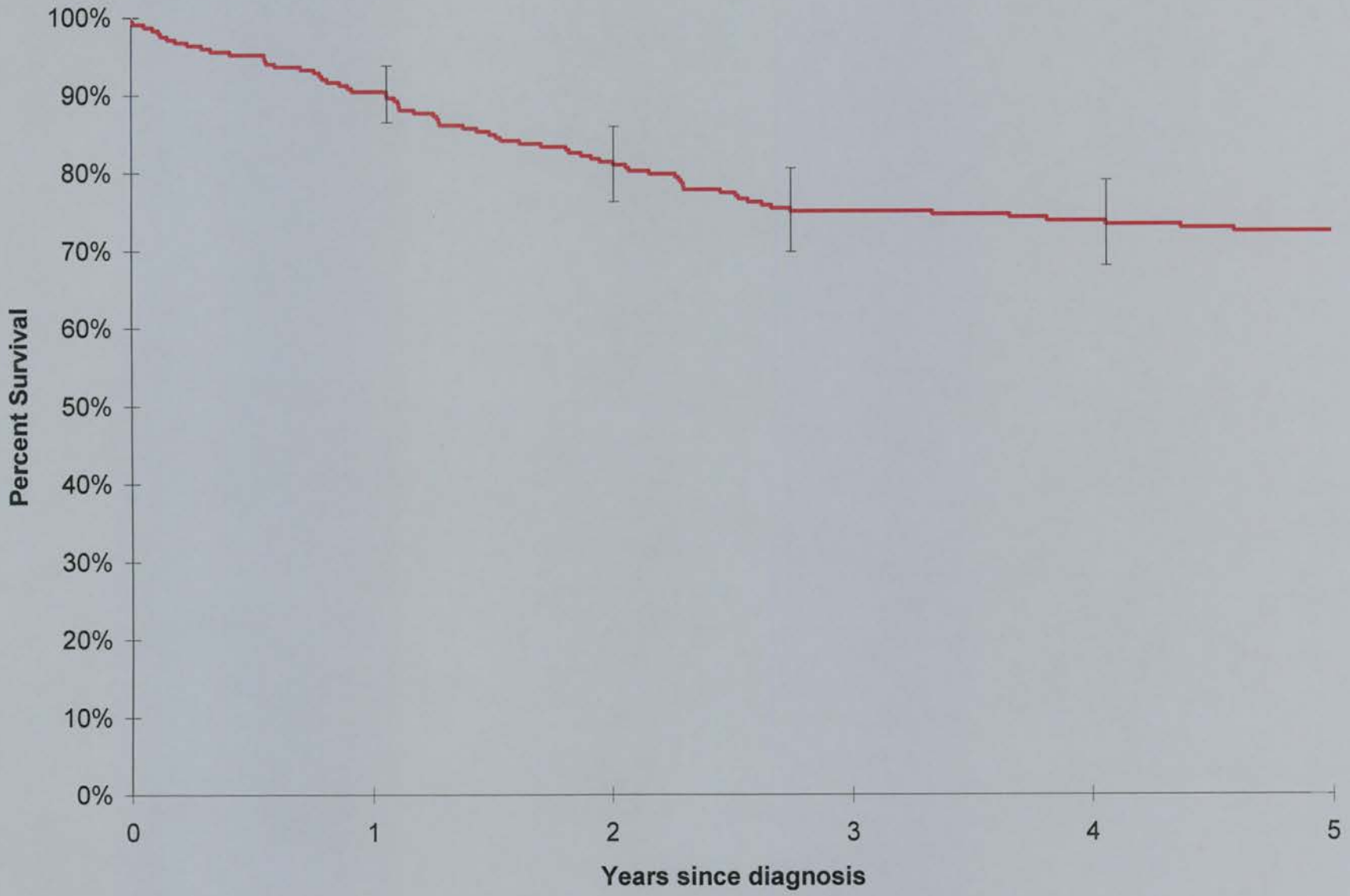
Cause of Death	Number of Cases	Number of Deaths	5 year survival rate %	Mortality : Incidence Ratio
Leukaemia (I)	140	76	50.4	54.3
Lymphoma (II)	330	64	84.0	19.4
CNS Tumours (III)	198	61	64.1	30.8
Sympathetic system tumours (IV)	16	12	78.3	75.0
Renal Tumours (VI)	6	2	66.6	33.3
Hepatic Tumours (VII)	3	3	0	100.0
Bone Tumours (VIII)	76	39	55.7	51.3
Soft tissue sarcomas (IX)	79	26	64.2	32.9
Germ cell tumours (X)	168	28	85.0	16.7
Carcinomas (XI)	326	71	87.3	21.8
Unspecified tumours (XII)	33	5	77.2	15.2
Total	1375	387	72.4	28.1

7.5.2 Five year survival by age band

Though not reaching statistical significance (p=.81), greater survival is seen in the older age groups (10-14 = 72.4; 15-19 = 74.3; 20-24 =72.4), again this may

Figure 7.19

Five Year Survival - All Cases



be a reflection of case mix, with more of the older group having proportionately fewer life threatening cancers. (figure 7.20)

7.5.3 Survival by Sex

Figure 7.21 suggests that five year survival in females is greater than males (76.4% and 74.2% respectively) (on the border of statistical significance, p=0.29) - this may be related to case mix. This is repeated in the Northern data. which does reach the level of statistical significance (p=0.02) in the comparison of the survival curves using the log rank test.

7.5.4 Survival by County of Residence

Figure 7.22 shows apparently different five year survival in the three main counties in the region. North Yorkshire (74.3%; county 37), Humberside (70.4%; county 28) and West Yorkshire (77.4%; county 8). Apparently better survival is demonstrated in West Yorkshire, followed by North Yorkshire and Humberside. This difference reaches statistical significance (p=0.02). A similar difference is seen in the Northern region data with an apparently worse survival rate in one of the counties (county Durham).

7.5.5 Survival by Hospital of Treatment

The categories shown in figure 7.23 are as follows:

Hospital category 1 = large teaching hospital - in practice Leeds or Hull

Hospital category 2 = large district hospital (more than 150 beds)

Hospital category 3 = small hospital (less than 150 beds)

Hospital category 4 = non Yorkshire hospital

Figure 7.20

Five Year Survival by Age Band

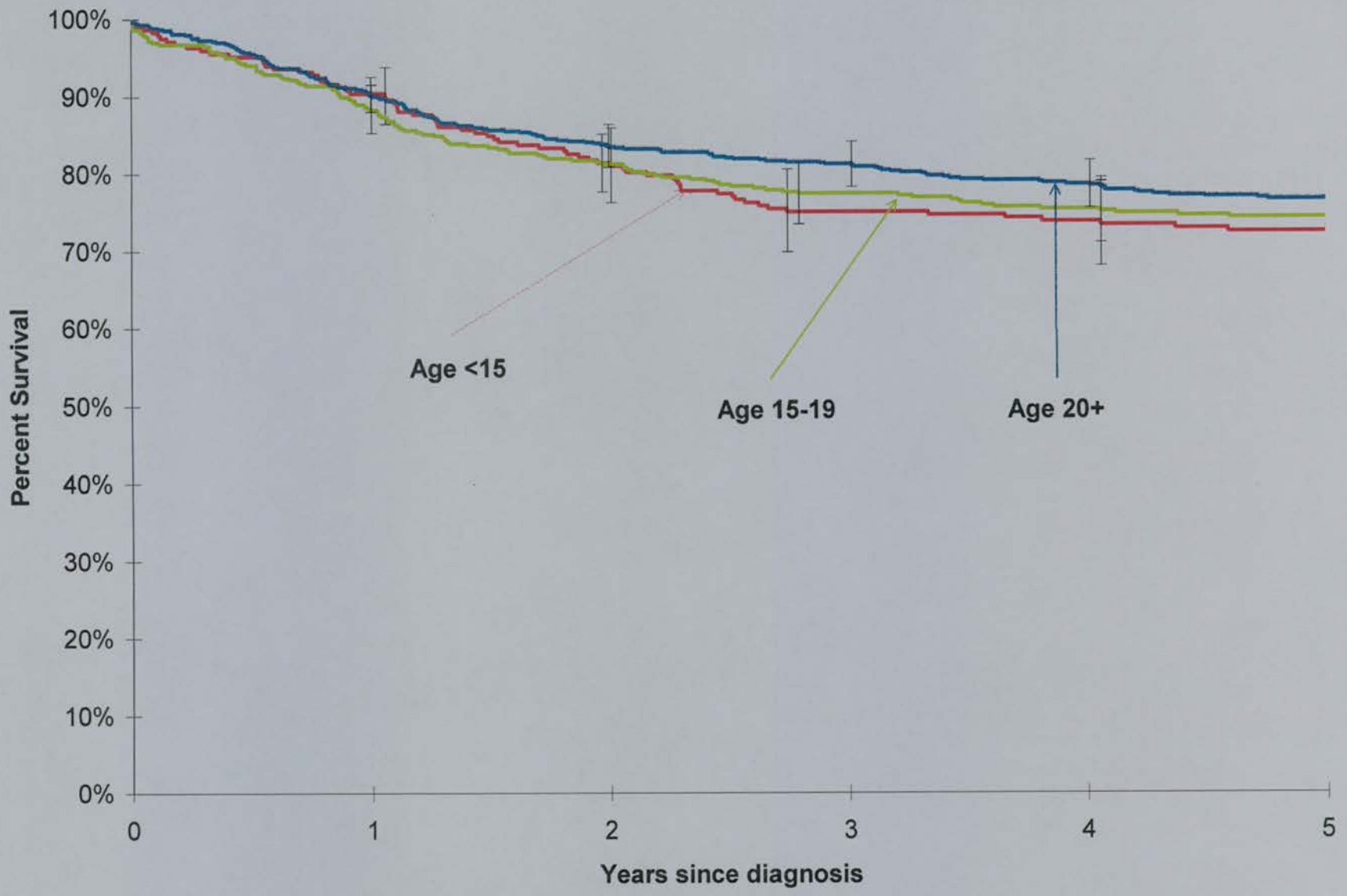


Figure 7.21

Five Year Survival by Sex

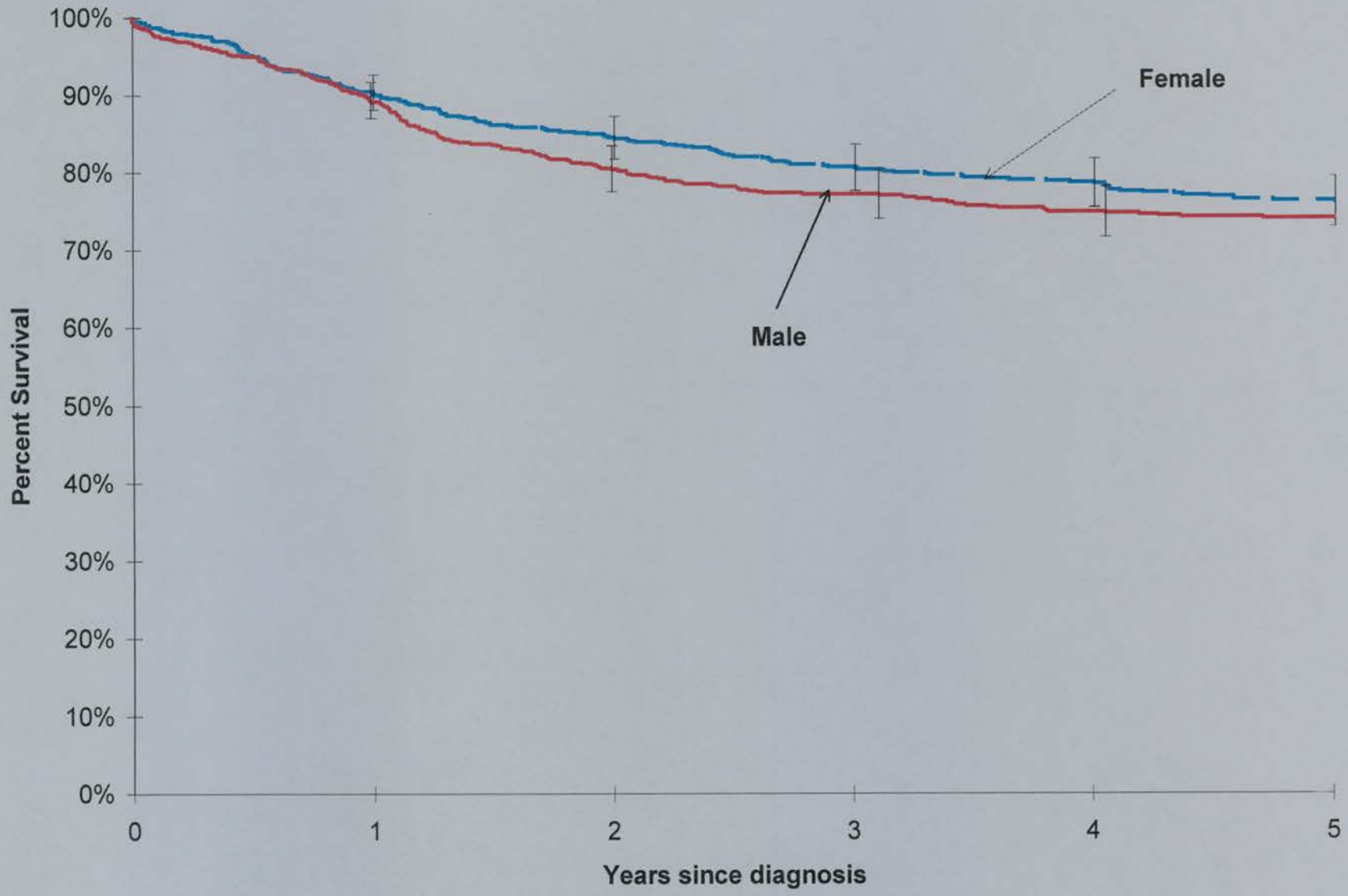


Figure 7.22

Five Year Survival by County of Residence

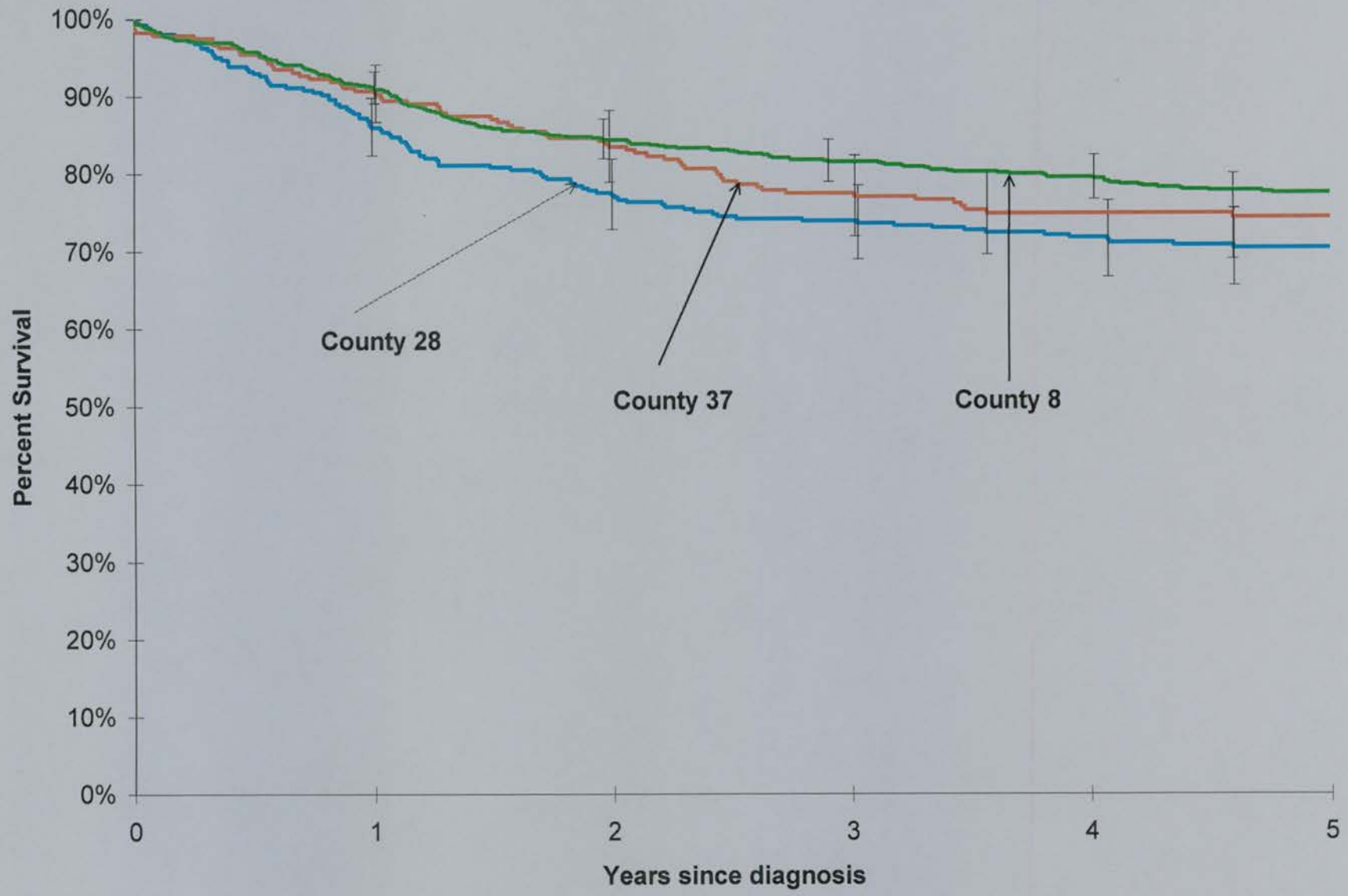


Figure 7.23

Five Year Survival by Hospital Type

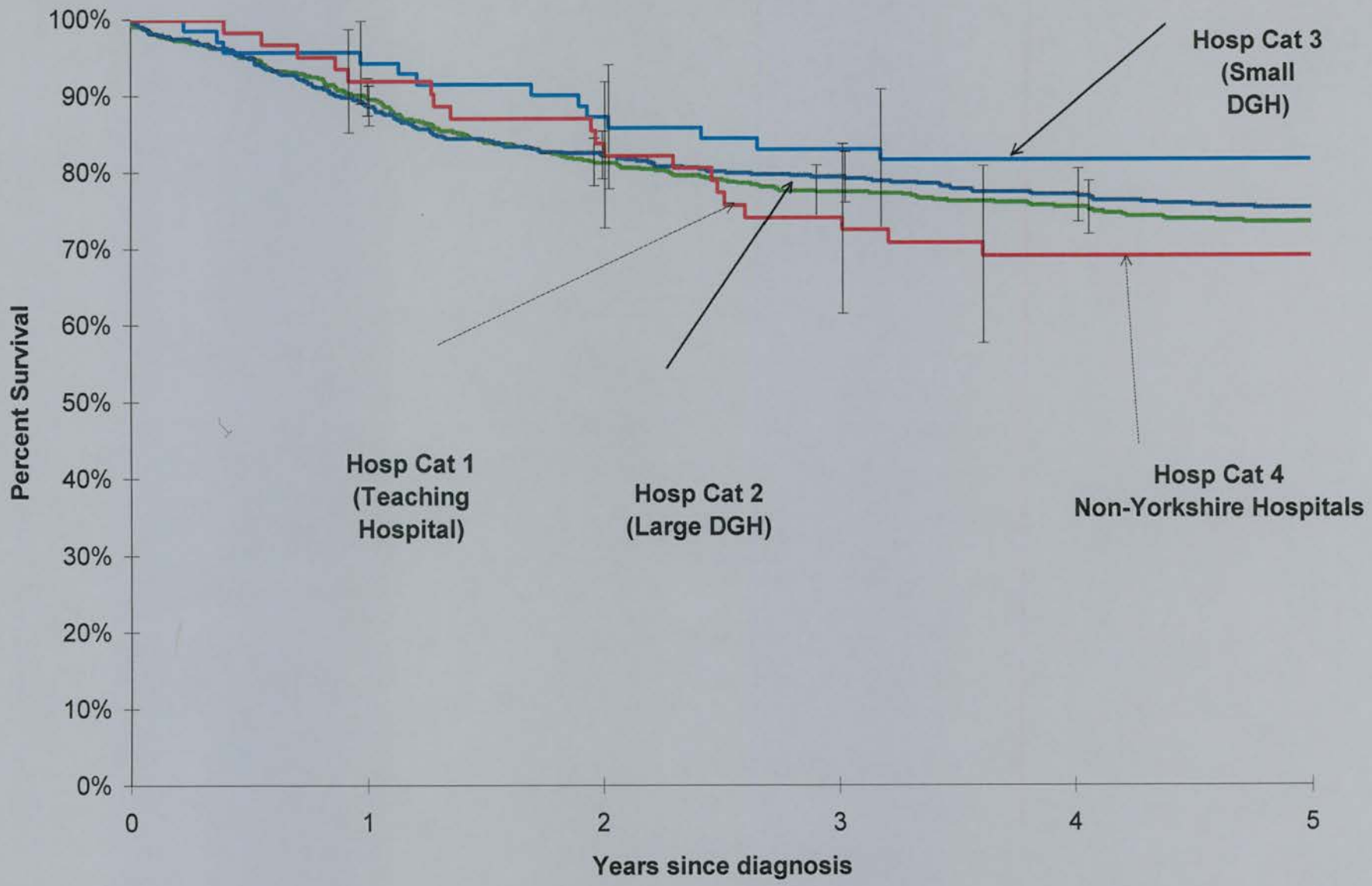
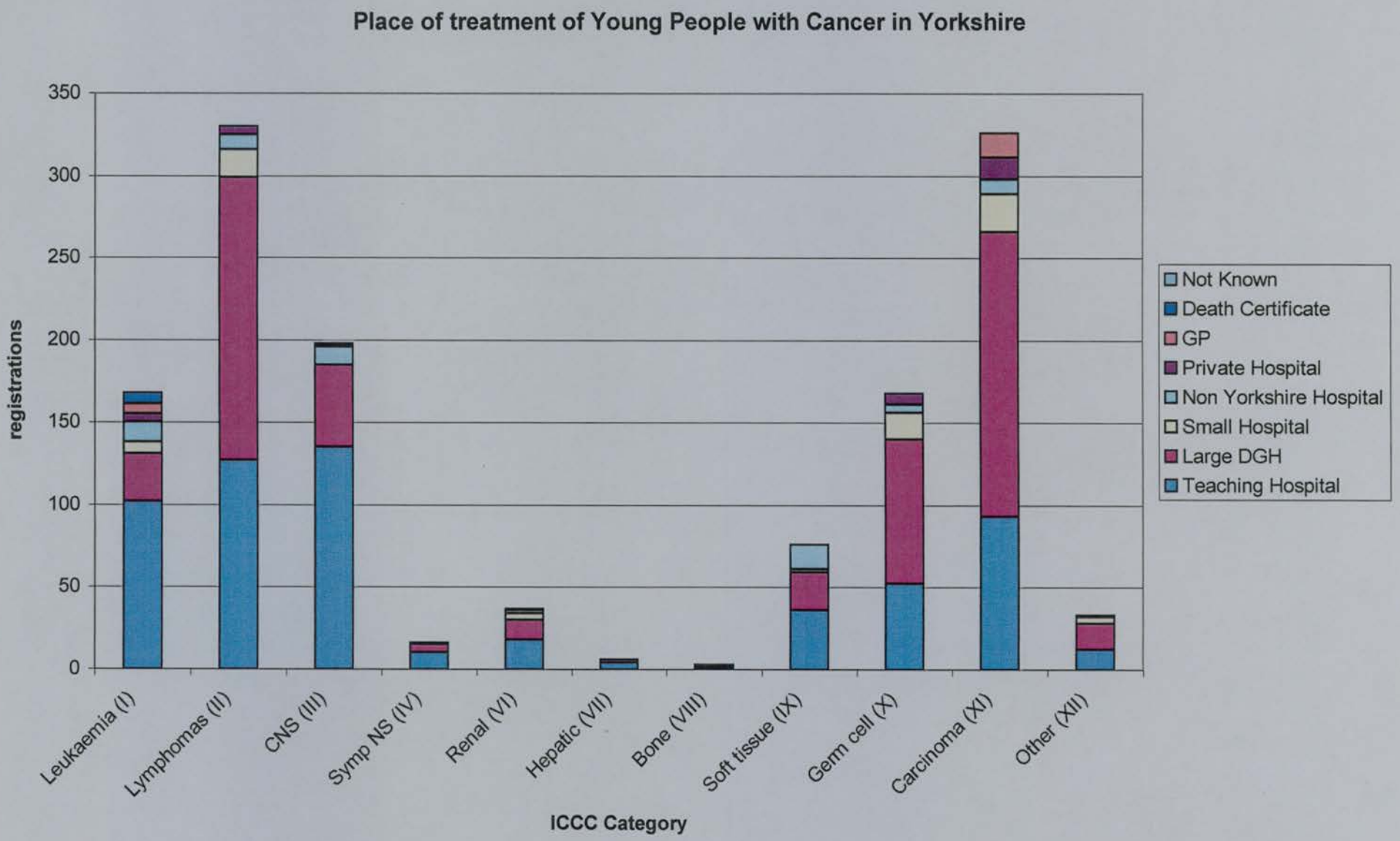


Figure 7.24


Place of treatment of Young People with Cancer in Yorkshire
registrations
350
300
250
200
150
100
50
0
Leukaemia (I)
Lymphomas (II)
CNS (III)
Symp NS (IV)
Renal (VI)
Hepatic (VII)
Bone (VIII)
Soft tissue (IX)
Germ cell (X)
Carcinoma (XI)
Other (XII)
ICCC Category
Not Known
Death Certificate
GP
Private Hospital
Non Yorkshire Hospital
Small Hospital
Large DGH
Teaching Hospital

Outcomes in small hospital appear best (five year survival = 81.7%), with hospitals in categories 3 having best outcome and 4 (five year survival = 69.1%) having poorest outcome, this could be due to casemix. A large proportion of hospitals in category 4 were London Teaching Hospitals. This issue is considered in some depth in the discussion. (p=0.42). In the Northern Region data, survival was notably poorer in those patients treated in the cancer centres, this is almost certainly explained by casemix which was not accounted for in the analysis.

7.5.6 Casemix of treatment units in Yorkshire

Figures 7.24 - 7.27 shows the differential casemix in the units of Yorkshire. Figure 7.25 illustrates the % of malignancies treated in the various units. It shows, as expected, that a higher % of patients with CNS malignancies are treated in major centres (neurosurgery does not occur outside major centres). The figures suggest a disproportionately low level of teaching hospital involvement in the treatment of lymphomas.

7.5.7 Survival by Year of Diagnosis

Figure 7.28 shows a marginally significant improvement in five year survival over the decade (p=0.092) 76.4% compared to 74.0%. Such an improvement over time was not noted in the Northern data.

7.5.8 Survival by diagnostic group

There will now be consideration of survival for each individual malignancy. Under each heading.

Figure 7.25

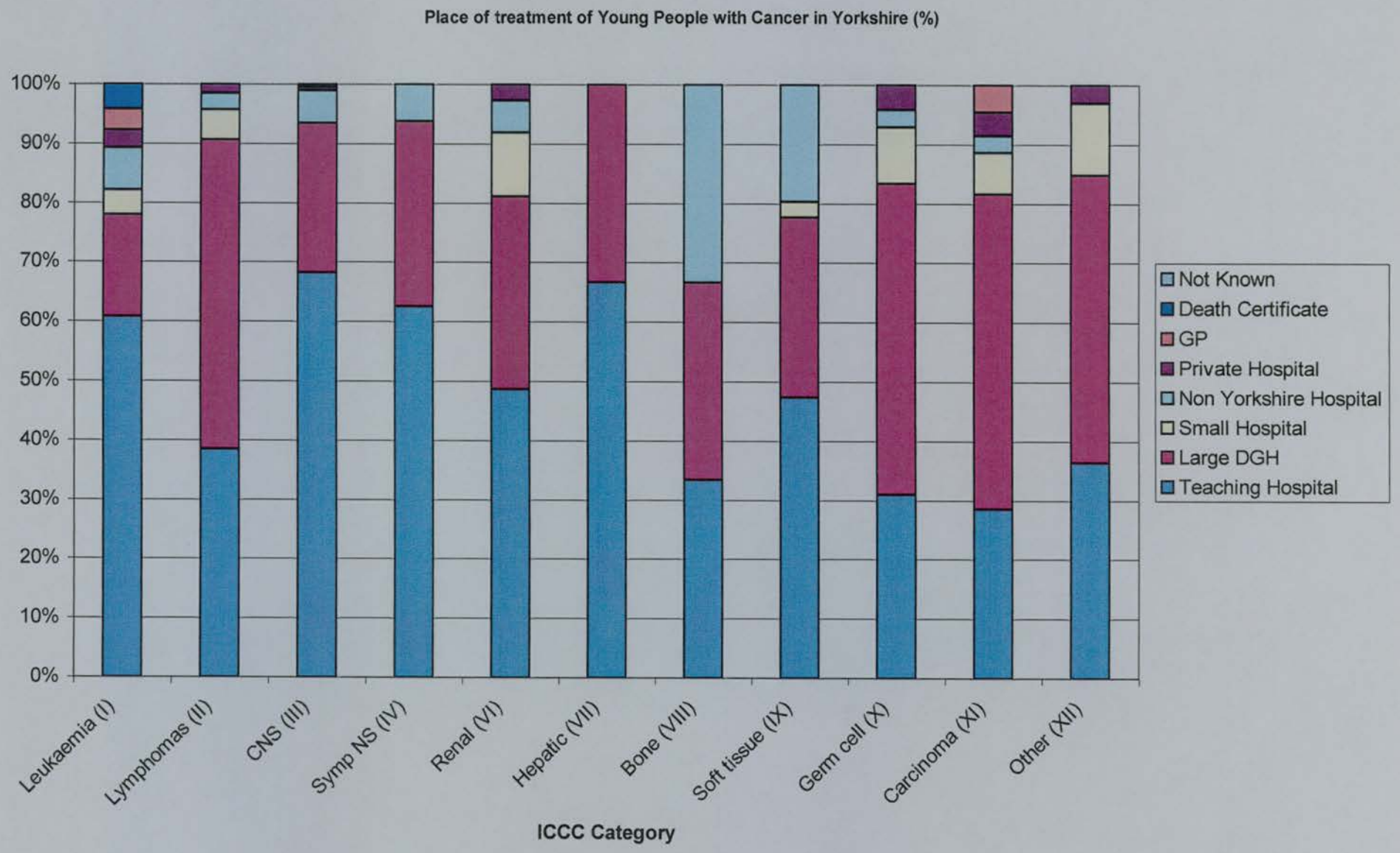

Place of treatment of Young People with Cancer in Yorkshire (%)
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
Leukaemia (I)
Lymphomas (II)
CNS (III)
Symp NS (IV)
Renal (VI)
Hepatic (VII)
Bone (VIII)
Soft tissue (IX)
Germ cell (X)
Carcinoma (XI)
Other (XII)
ICCC Category
Not Known
Death Certificate
GP
Private Hospital
Non Yorkshire Hospital
Small Hospital
Large DGH
Teaching Hospital

Figure 7.26

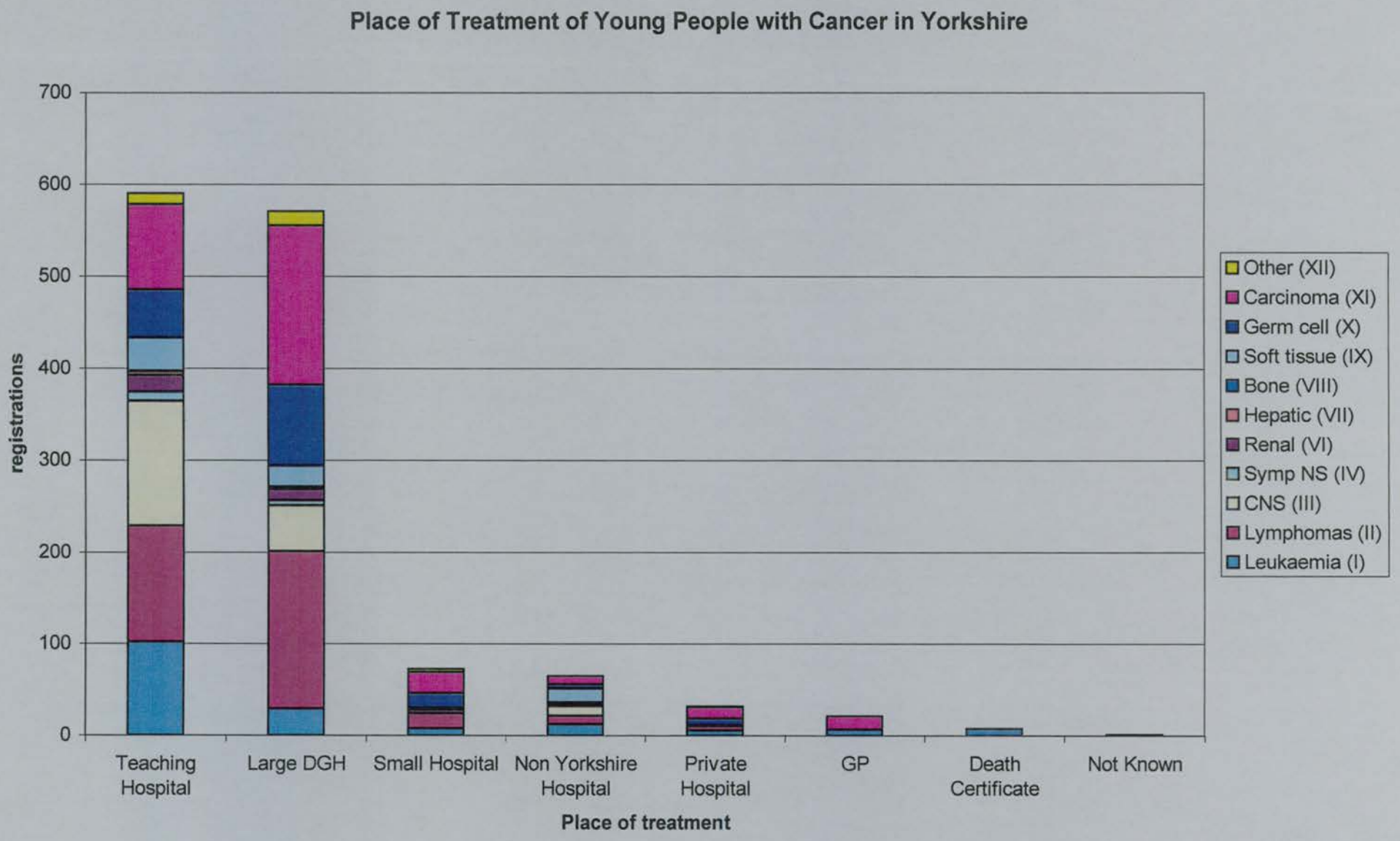

Place of Treatment of Young People with Cancer in Yorkshire
700
600
500
400
300
200
100
0
registrations
Other (XII)
Carcinoma (XI)
Germ cell (X)
Soft tissue (IX)
Bone (VIII)
Hepatic (VII)
Renal (VI)
Symp NS (IV)
CNS (III)
Lymphomas (II)
Leukaemia (I)
Teaching Hospital
Large DGH
Small Hospital
Non Yorkshire Hospital
Private Hospital
GP
Death Certificate
Not Known
Place of treatment

Figure 7.27

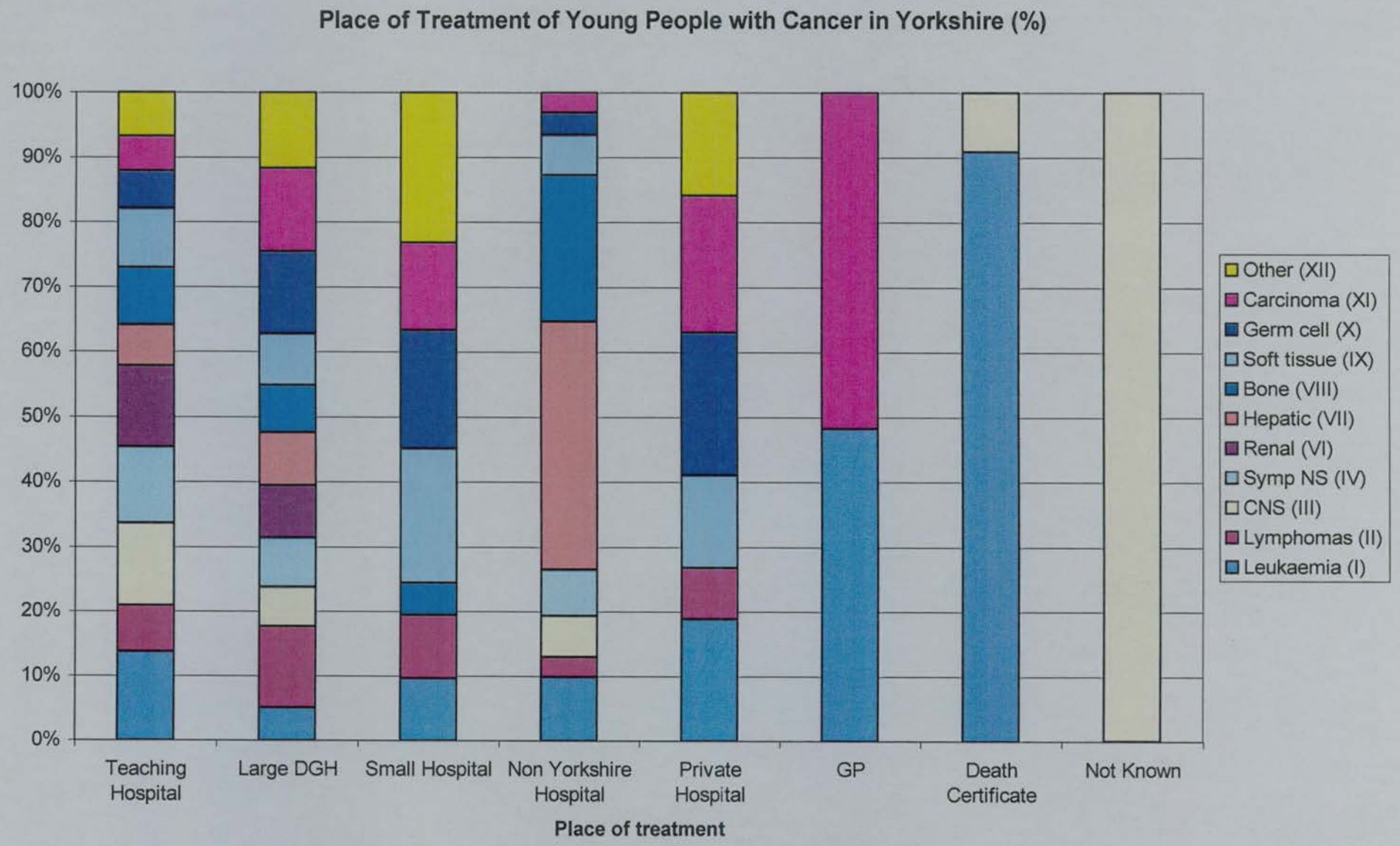

Place of Treatment of Young People with Cancer in Yorkshire (%)
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
Other (XII)
Carcinoma (XI)
Germ cell (X)
Soft tissue (IX)
Bone (VIII)
Hepatic (VII)
Renal (VI)
Symp NS (IV)
CNS (III)
Lymphomas (II)
Leukaemia (I)
Teaching Hospital
Large DGH
Small Hospital
Non Yorkshire Hospital
Private Hospital
GP
Death Certificate
Not Known
Place of treatment

Figure 7.28

Five Year Survival by Year of Diagnosis

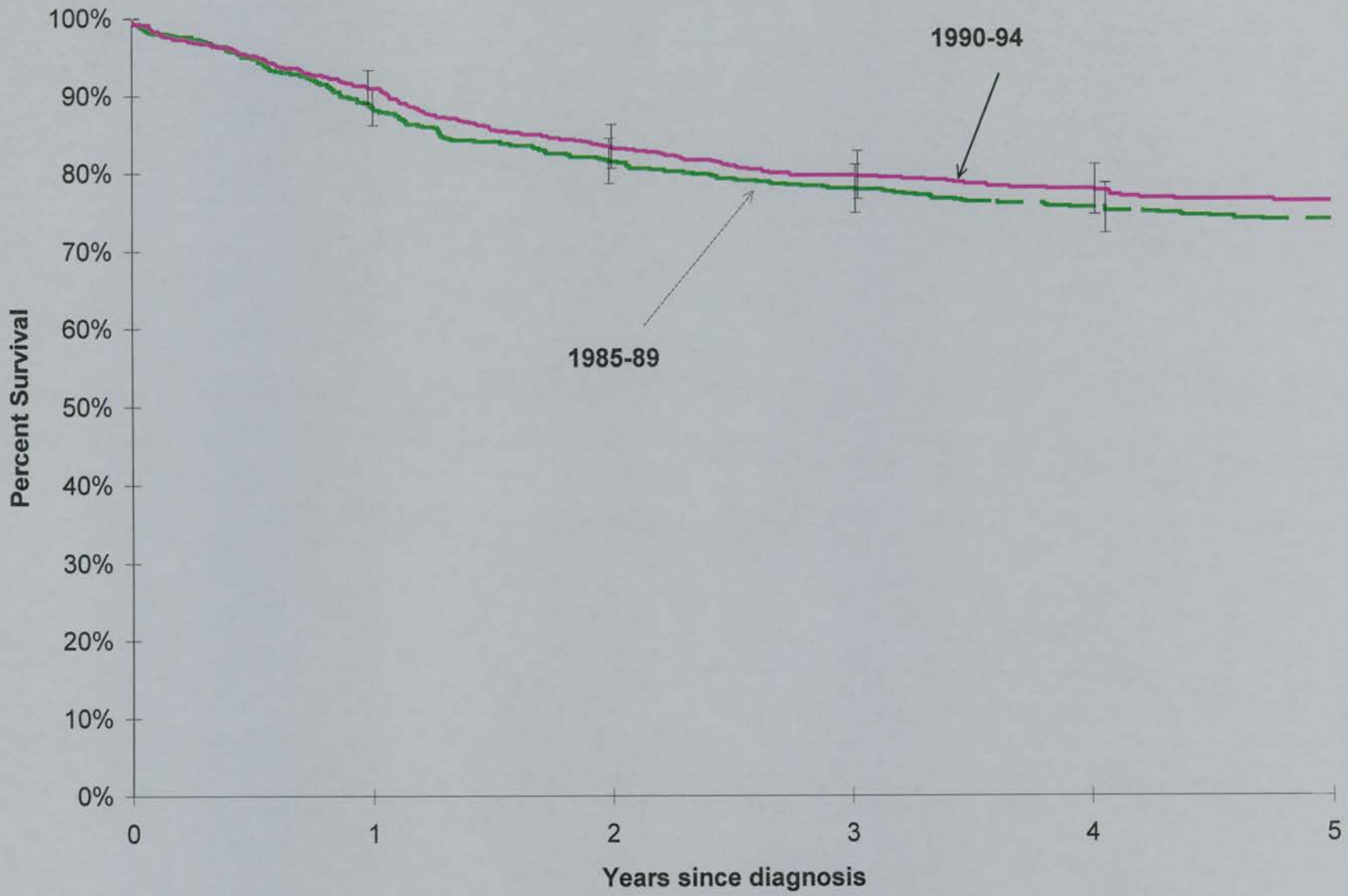
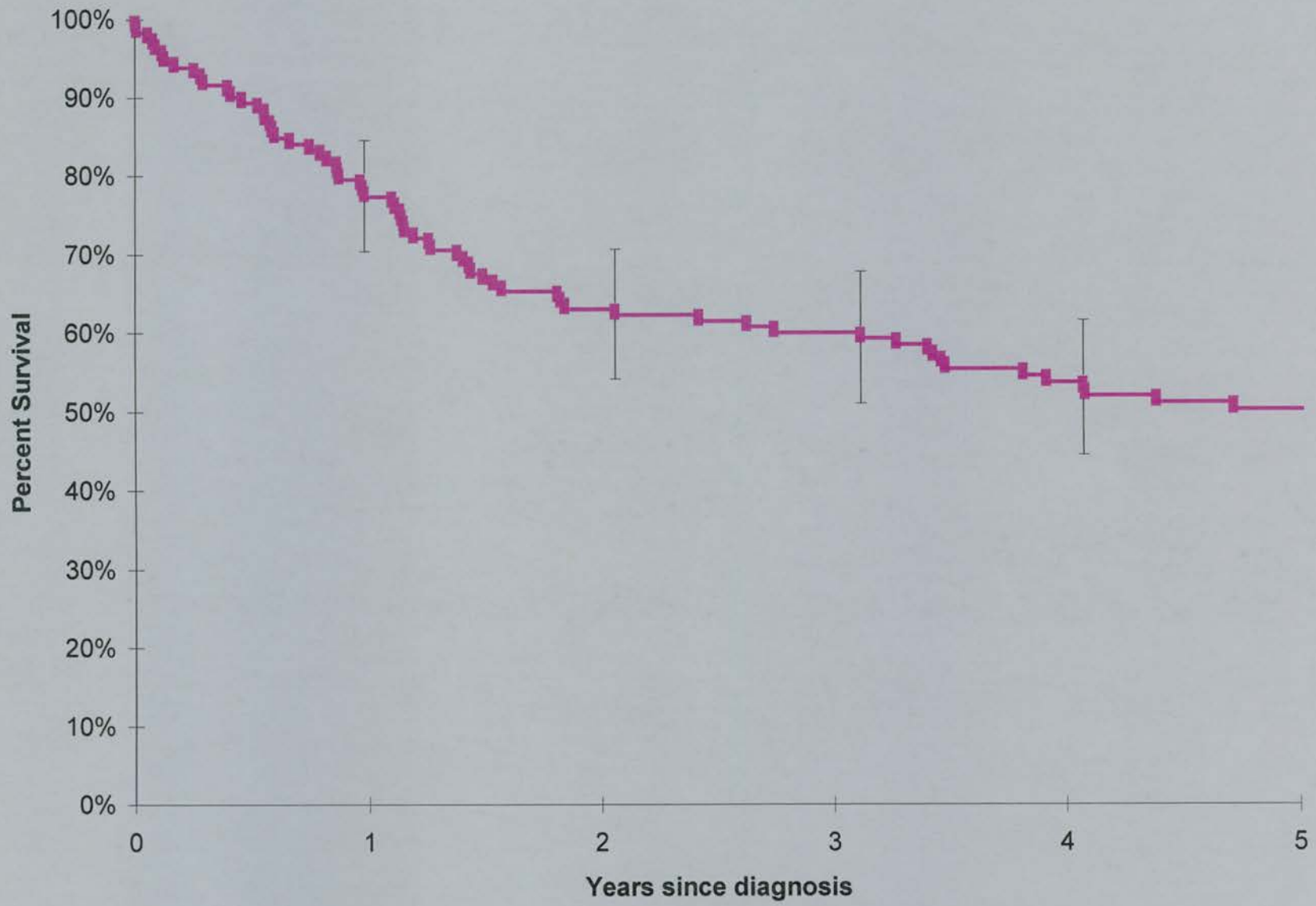


Figure 7.29

Five Year Survival for Leukaemia



7.5.8.1 Leukaemia

For leukaemia there were 140 cases, and 76 deaths. The vast majority of these deaths occurred in patients who had received treatment in a teaching hospital as shown in table 7.20. The survival curve is shown in figure 7.29

Figure 7.30

Five Year Survival for Lymphoma

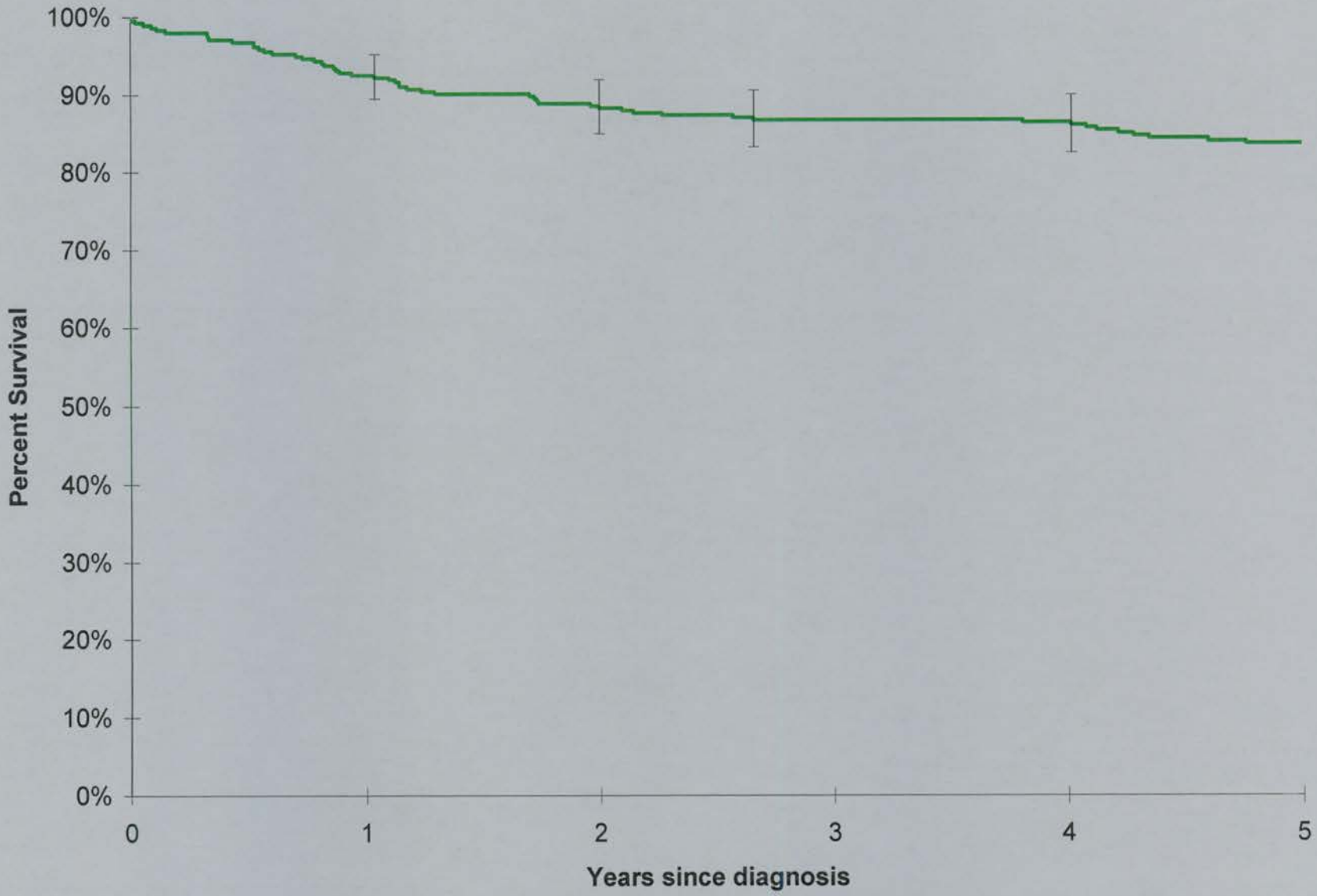


Figure 7.31

Five Year Survival for CNS Tumours

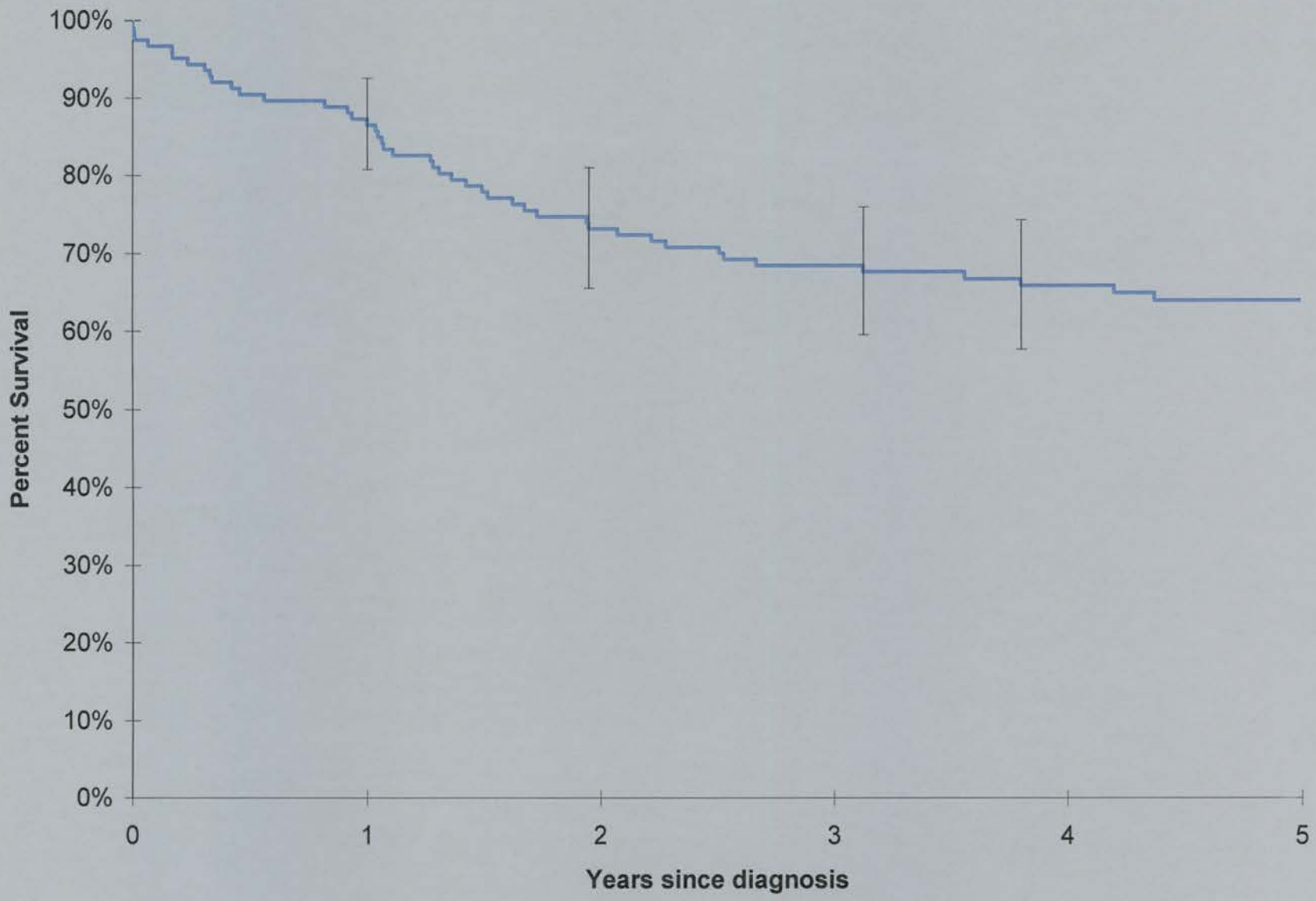


Table 7.20 Cases of and deaths from leukaemia by setting

Main source of care	Deaths	Cases	% deaths in each setting
Teaching Hospital	46	101	60.5
Large non-teaching hospital	15	27	19.7
Small non-teaching hospital	4	4	5.3
Non Yorkshire hospital	1	8	1.3
Private hospital	0	0	0
Death certificate registration	0	0	0
Unknown	0	0	0
Total	76	140	100

7.5.8.2 Lymphoma Survival

For lymphoma there were 331 cases and 64 deaths as shown in table 7.21. In this case more deaths occurred in patients treated in large district hospital, reflecting the place of treatment of most patients with lymphoma. The survival curve is shown in figure 7.30

Table 7.21 Cases of and deaths from lymphoma by setting

Main source of care	Deaths	Cases	% deaths in each setting
Teaching Hospital	27	127	42.2
Large non-teaching hospital	33	173	51.6
Small non-teaching hospital	1	17	1.6
Non Yorkshire hospital	1	9	1.6
Private hospital	2	5	3.1
Death certificate registration	0	0	0
Unknown	0	0	0
Total	64	331	100

7.5.8.3 CNS Tumours Survival

For CNS tumours there were 198 cases and 61 deaths. Table 7.22 shows how these deaths were distributed by place of treatment. Survival curves are shown in figure 7.31

Figure 7.32

Five Year Survival for Sympathetic Tumours

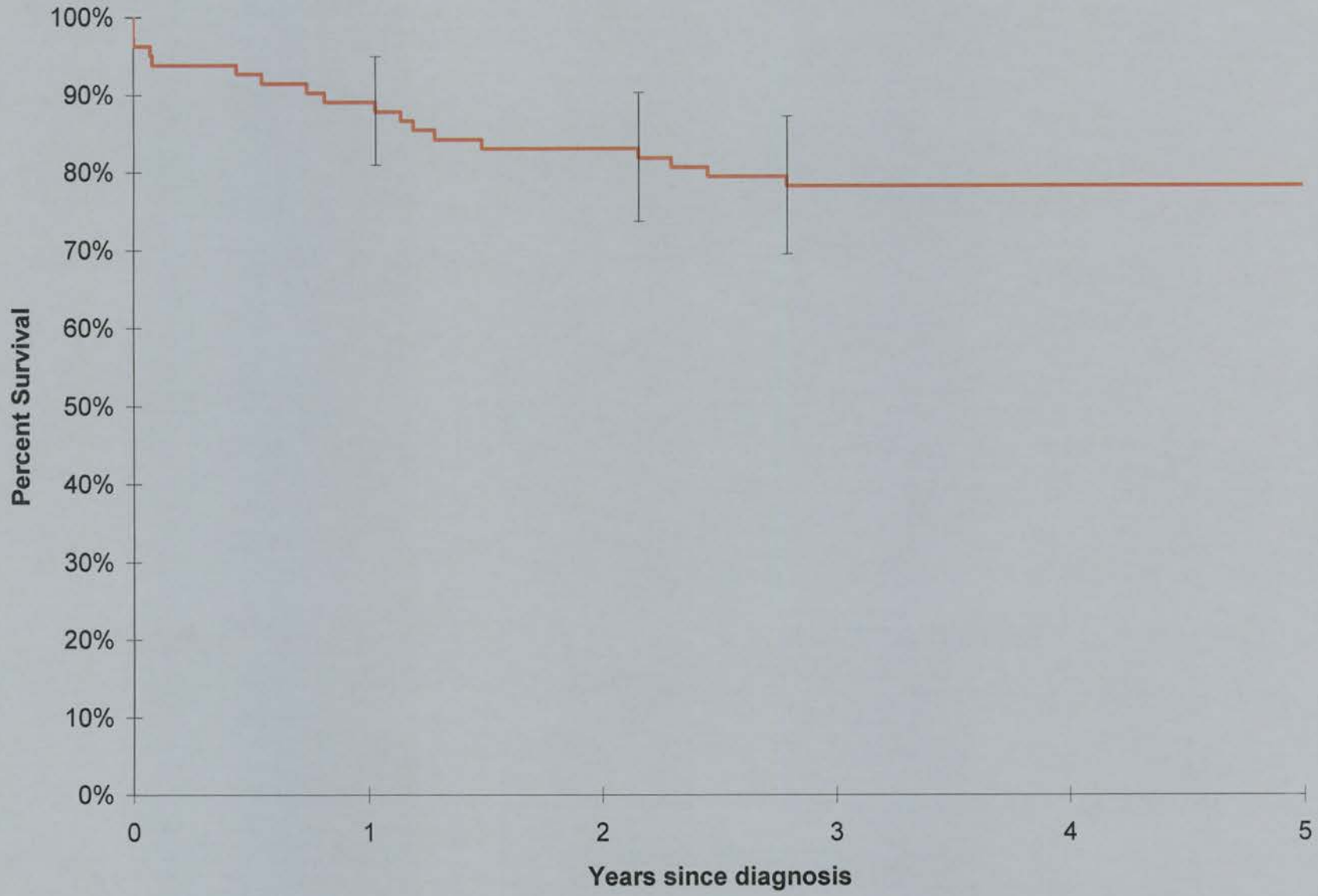


Figure 7.33

Five Year Survival for Renal Tumours

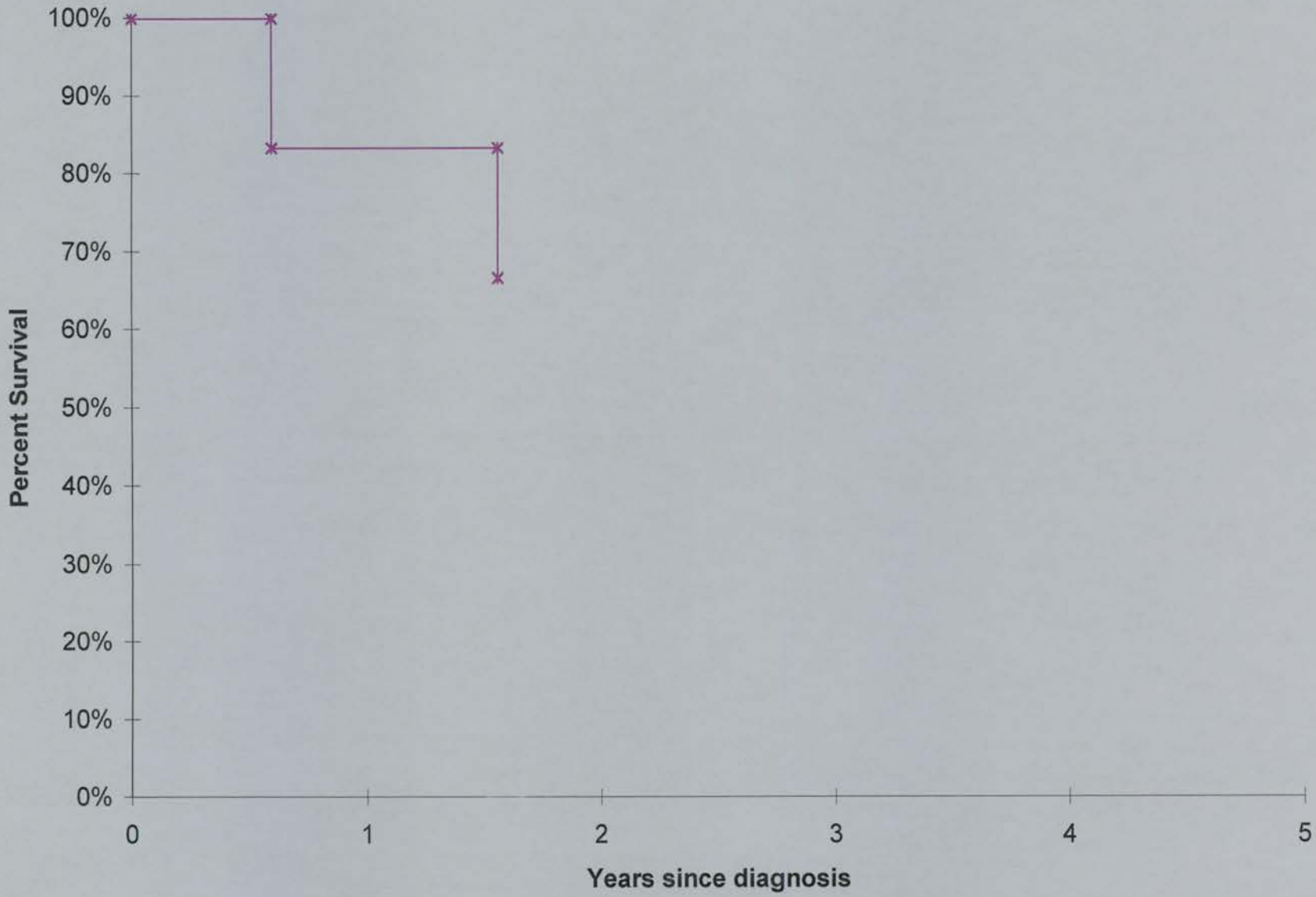


Table 7.22 Cases of and deaths from CNS Tumours by setting

Main source of care	Deaths	Cases	% deaths in each setting
Teaching Hospital	39	135	63.9
Large non-teaching hospital	18	50	29.5
Small non-teaching hospital	0	0	0
Non Yorkshire hospital	2	11	3.3
Private hospital	0	0	0
Death certificate registration	1	1	1.6
Unknown	1	1	1.6
Total	61	198	100

7.5.8.4 Sympathetic Tumours Survival

For sympathetic nervous system tumours there were 16 cases and 12 deaths. Table 7.23 shows how these deaths were distributed by place of treatment. Survival curves are shown in figure 7.32

Table 7.23 Cases of and deaths from sympathetic tumours by setting

Main source of care	Deaths	Cases	% deaths in each institution
Teaching Hospital	7	10	58.3
Large non-teaching hospital	4	5	33.3
Small non-teaching hospital	0	0	0
Non Yorkshire hospital	1	1	8.3
Private hospital	0	0	0
Death certificate registration	0	0	0
Unknown	0	0	0
Total	12	16	100

7.5.8.5 Renal Tumours Survival

For renal tumours there were 6 cases and 2 deaths. Table 7.24 shows how these deaths were distributed by place of treatment. Survival curves are shown in figure 7.33

Table 7.24 Cases of and deaths from renal tumours by setting

Figure 7.34

Five Year Survival for Hepatic Tumours

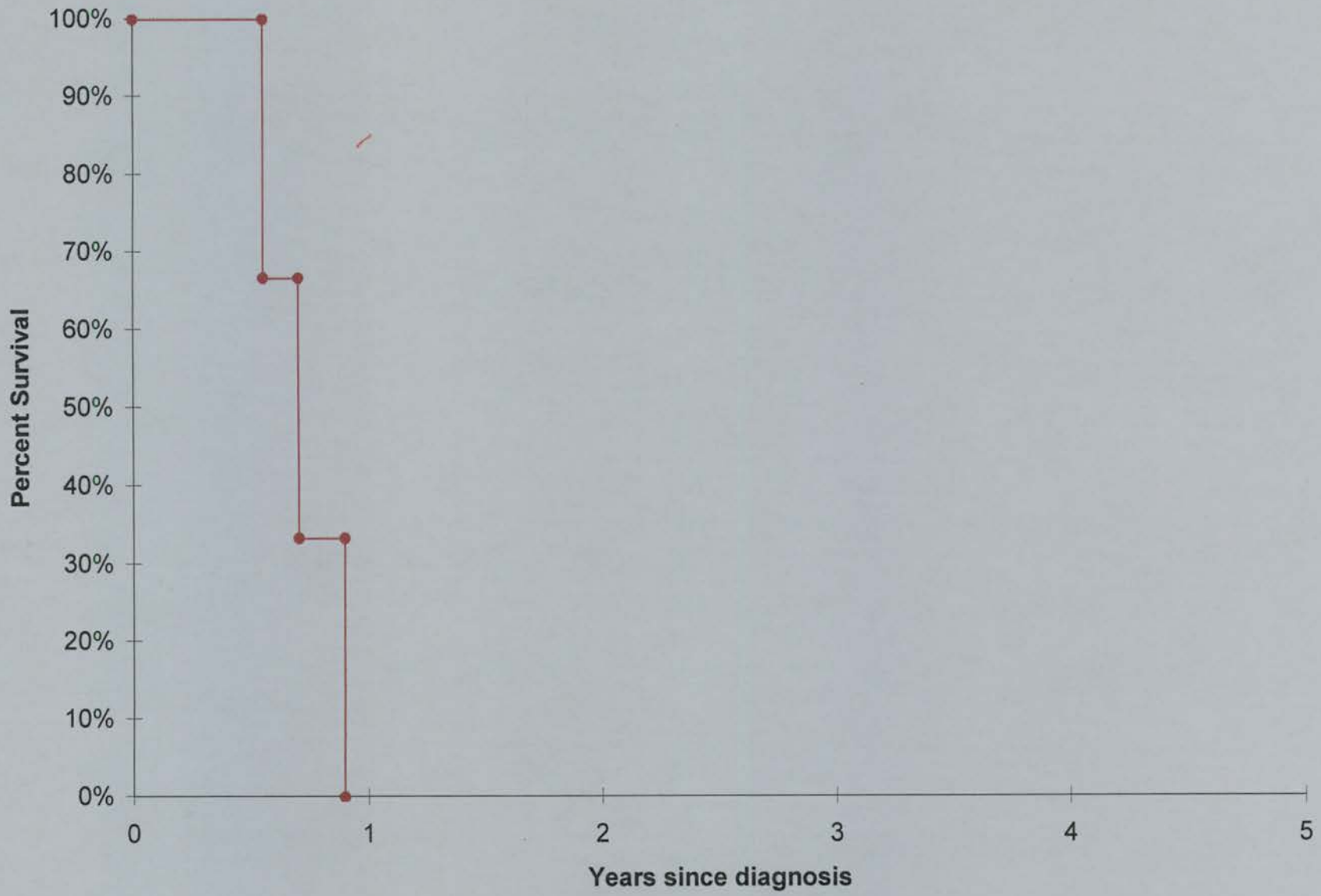
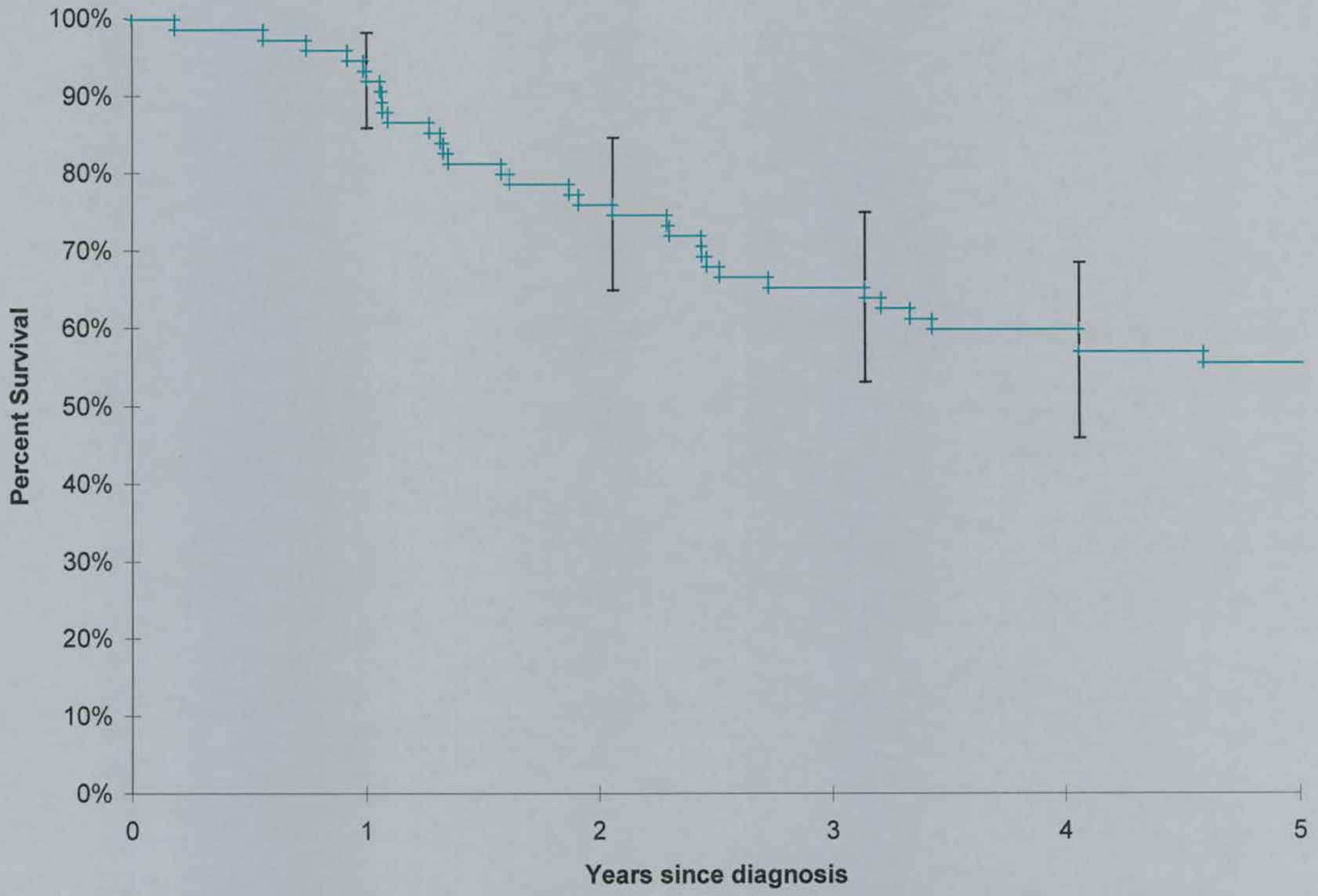


Figure 7.35

Five Year Survival for Bone Tumours



Main source of care	Deaths	Cases	% deaths in each setting
Teaching Hospital	1	4	50
Large non-teaching hospital	1	2	50
Small non-teaching hospital	0	0	0
Non Yorkshire hospital	0	0	0
Private hospital	0	0	0
Death certificate registration	0	0	0
Unknown	0	0	0
Total	2	6	100

7.5.8.6 Hepatic Tumours Survival

For hepatic tumours there were 3 cases and 3 deaths confirming the poor prognosis for hepatic malignancy in this age group. Table 7.25 shows how these deaths were distributed by place of treatment. Survival curves are shown in figure 7.34

Table 7.25 Cases of and deaths from hepatic tumours by setting

Main source of care	Deaths	Cases	% deaths in each setting
Teaching Hospital	1	1	33.3
Large non-teaching hospital	1	1	33.3
Small non-teaching hospital	0	0	0
Non Yorkshire hospital	1	1	33.3
Private hospital	0	0	0
Death certificate registration	0	0	0
Unknown	0	0	0
Total	3	3	100

7.5.8.7 Bone Tumours Survival

For bone tumours there were 76 cases and 39 deaths. Table 7.26 shows how these deaths were distributed by place of treatment. Survival curves are shown in figure 7.35

Figure 7.36

Five Year Survival in Soft Tissue Sarcomas

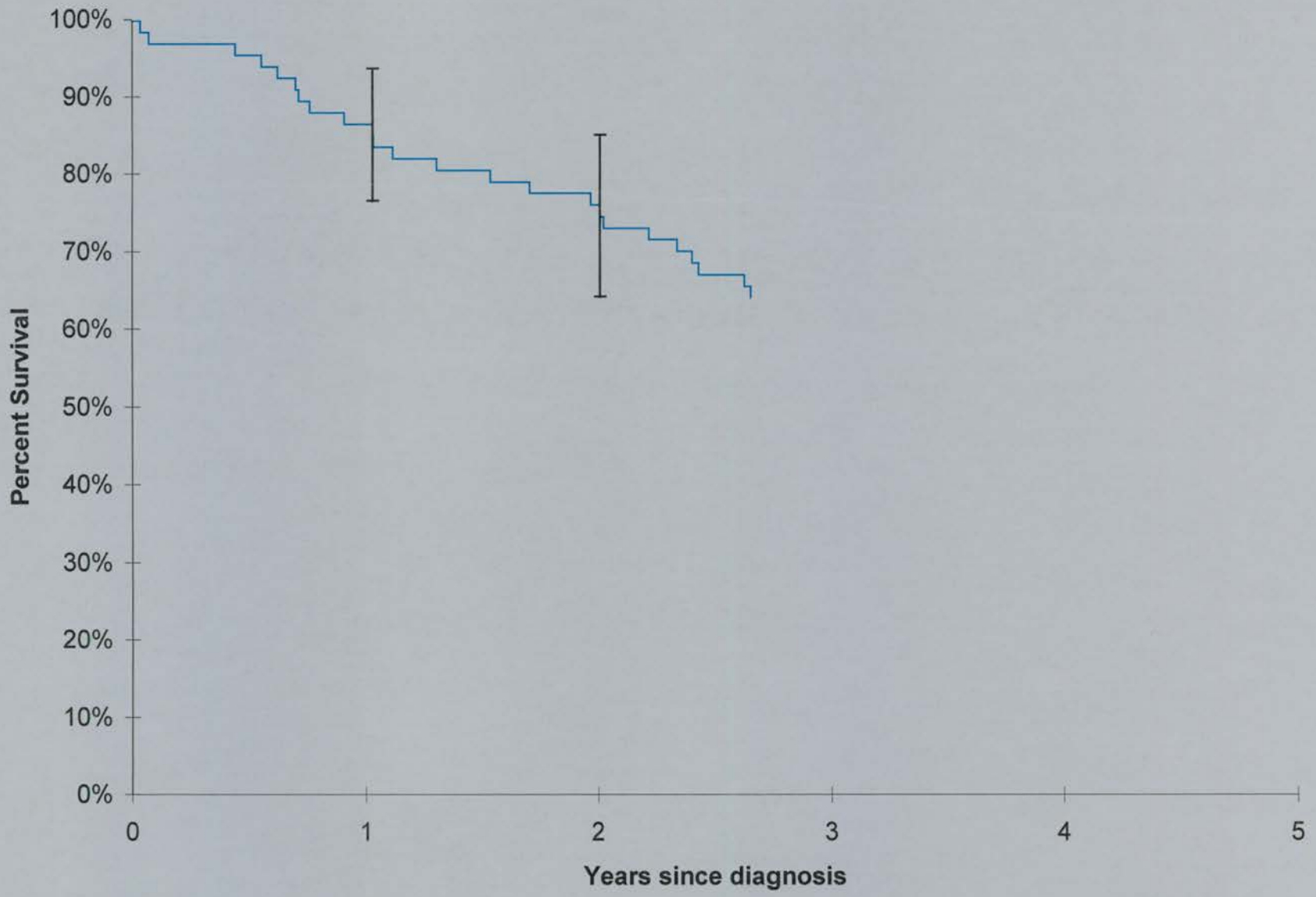


Table 7.26 Cases of and deaths from bone tumours by setting

Main source of care	Deaths	Cases	% deaths in each setting
Teaching Hospital	16	36	41.0
Large non-teaching hospital	15	23	38.5
Small non-teaching hospital	0	2	0
Non Yorkshire hospital	0	15	0
Private hospital	0	0	0
Death certificate registration	0	0	0
Unknown	0	0	0
Total	31	76	100

7.5.8.8 Soft Tissue Sarcomas Survival

For soft tissue sarcomas there were 79 cases and 26 deaths. Table 7.27 shows how these deaths were distributed by place of treatment. Survival curves are shown in figure 7.36

Table 7.27 Cases of and deaths from soft tissue sarcomas by setting

Main source of care	Deaths	Cases	% deaths in each setting
Teaching Hospital	11	36	42.3
Large non-teaching hospital	11	31	42.3
Small non-teaching hospital	2	6	7.7
Non Yorkshire hospital	2	5	7.7
Private hospital	0	1	0
Death certificate registration	0	0	0
Unknown	0	0	0
Total	26	79	100

7.5.8.9 Germ Cell Tumours Survival

For germ cell tumours there were 168 cases and 28 deaths. Table 7.28 shows how these deaths were distributed by place of treatment. Survival curves are shown in figure 7.37

Table 7.28 Cases of and deaths from germ cell tumours by setting

Main source of care	Deaths	Cases	% deaths in each setting
Teaching Hospital	3	52	10.7
Large non-teaching hospital	21	88	75.0
Small non-teaching hospital	2	16	7.1
Non Yorkshire hospital	2	5	7.1
Private hospital	0	7	0
Death certificate registration	0	0	0
Unknown	0	0	0
Total	28	168	100

Figure 7.37

Five Year Survival in Germ Cell Tumours

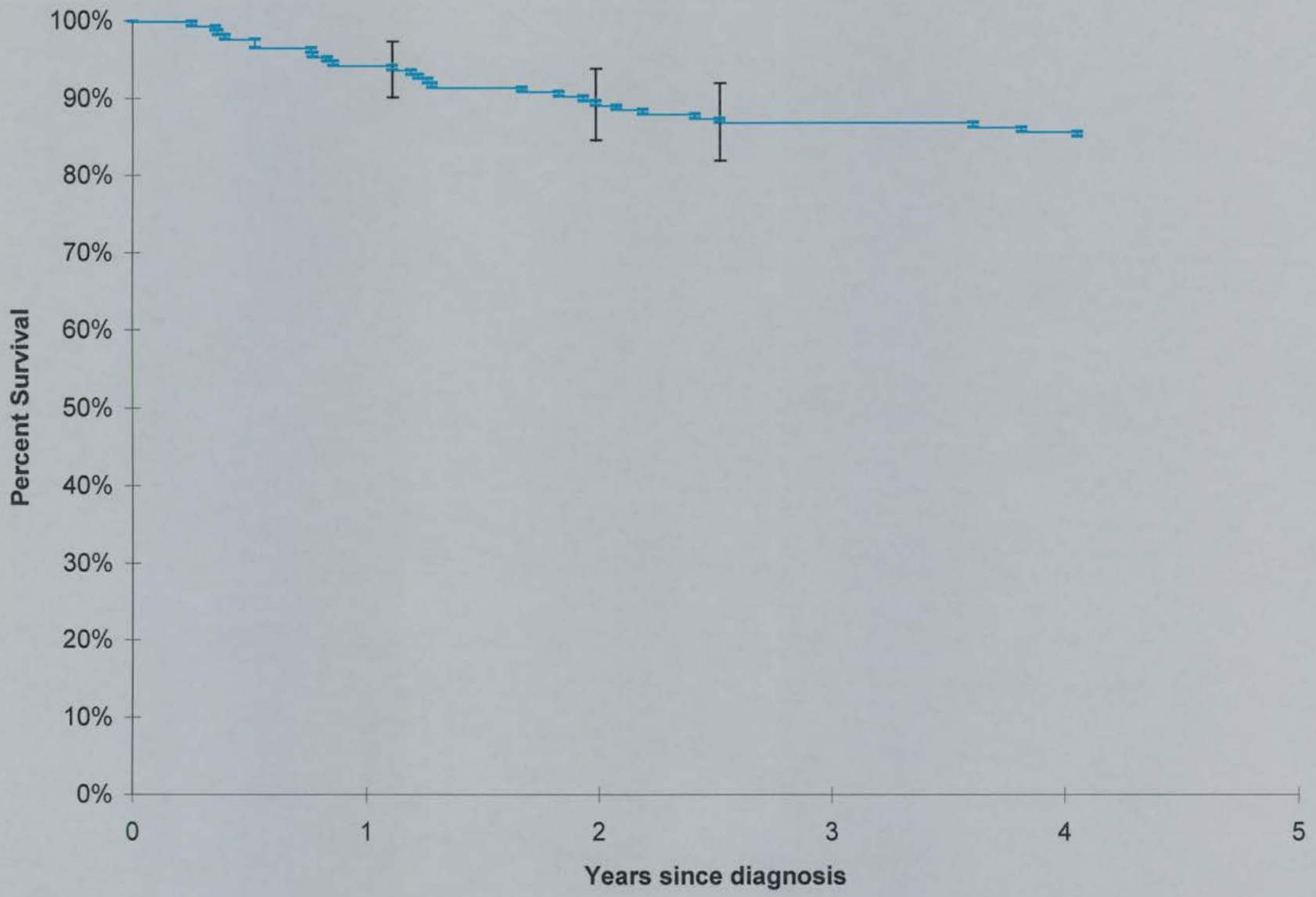


Figure 7.38

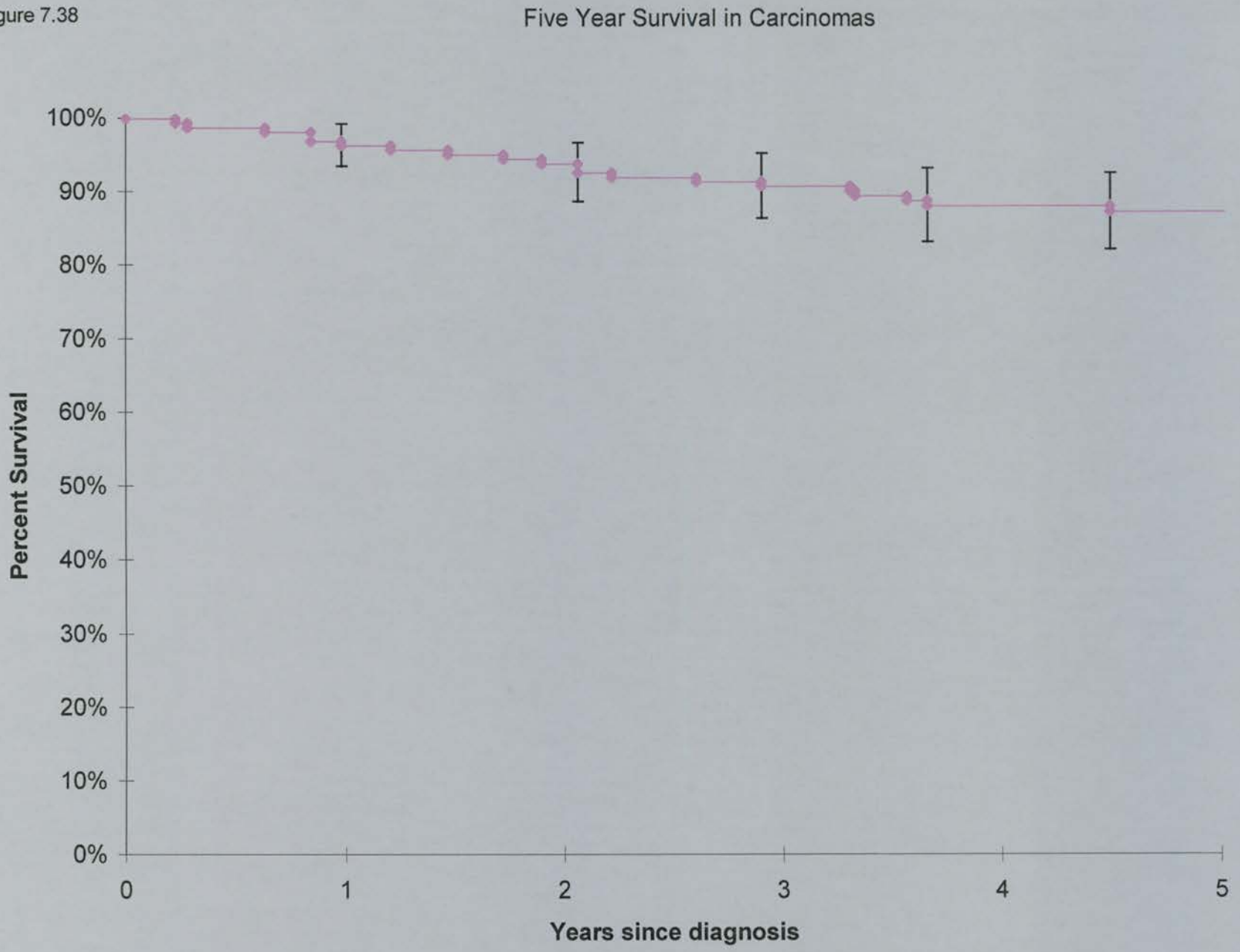
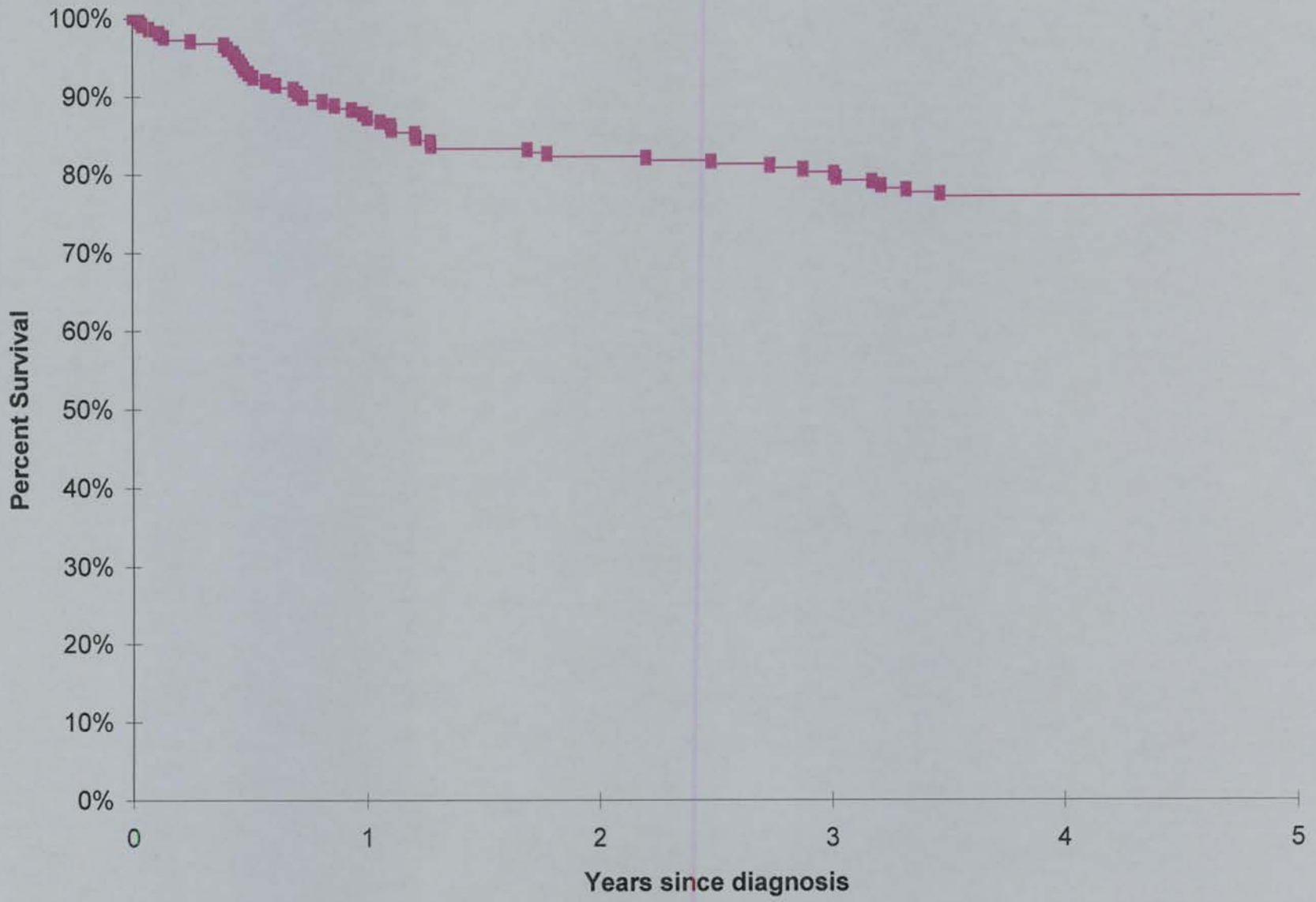

Five Year Survival in Carcinomas
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
Percent Survival
0
1
2
3
4
5
Years since diagnosis

Figure 7.39

Five Year Survival in Other Tumours



7.5.8.10 Carcinomas Survival

For carcinomas there were 326 cases and 28 deaths. Table 7.29 shows how these deaths were distributed by place of treatment. Survival curves are shown in figure 7.38

Table 7.29 Cases of and deaths from carcinomas by setting

Main source of care	Deaths	Cases	% deaths in each setting
Teaching Hospital	22	93	31.0
Large non-teaching hospital	37	173	52.1
Small non-teaching hospital	6	23	8.5
Non Yorkshire hospital	5	9	7.0
Private hospital	1	13	1.4
Death certificate registration	0	0	0
Unknown	0	13	0
Total	71	326	100

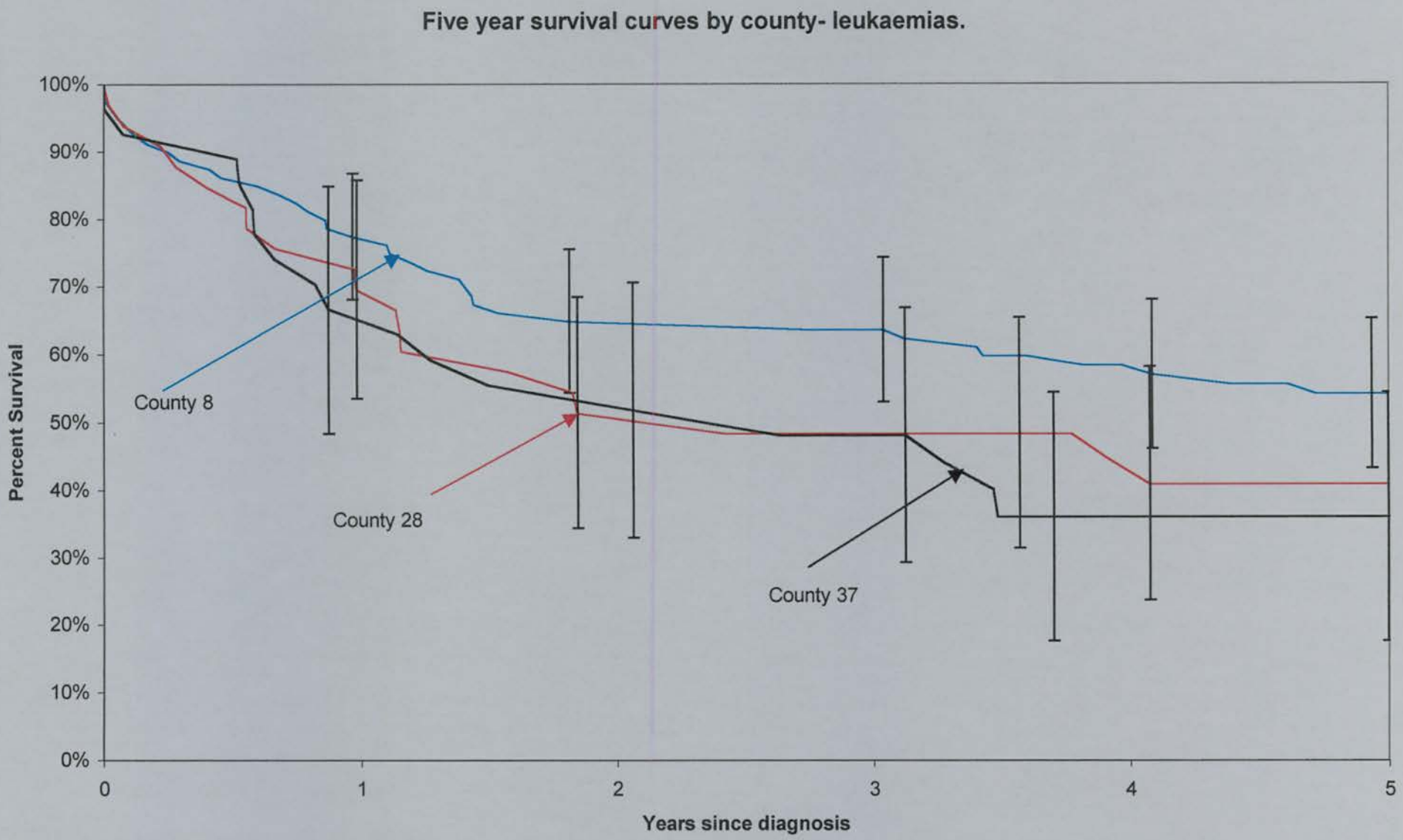
7.5.8.11 Other Tumours Survival

For other tumours there were 32 cases and 6 deaths. Table 7.30 shows how these deaths were distributed by place of treatment. Survival curves are shown in figure 7.39

Table 7.30 Cases and deaths from other tumours by setting

Main source of care	Deaths	Cases	% deaths in each setting
Teaching Hospital	2	12	33.3
Large non-teaching hospital	4	15	66.7
Small non-teaching hospital	0	4	0
Non Yorkshire hospital	0	0	0
Private hospital	0	1	0
Death certificate registration	0	0	0
Unknown	0	0	0
Total	6	32	100

Figure 7.40


Five year survival curves by county- leukaemias.
Percent Survival
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
0
1
2
3
4
5
Years since diagnosis
County 8
County 28
County 37

7.5.8.12 Survival by county by main diagnosis

A survival curve has already been shown for all groups of cancers by county (figure 7.22). The following curves (figures 7.40 - 44) show survival for each main cancer group. The differences which are demonstrated do not reach statistical significance (p values are shown on each figure from log rank tests). [County 8 = West Yorkshire; County 28 = Humberside; County 37 = North Yorkshire].

The patterns are broadly similar showing best survival in leukaemia in West Yorkshire, with West Yorkshire showing consistently better survival with the exception of carcinomas. Humberside shows consistently poor survival, perhaps with the exception of leukaemias.

Figure 7.41

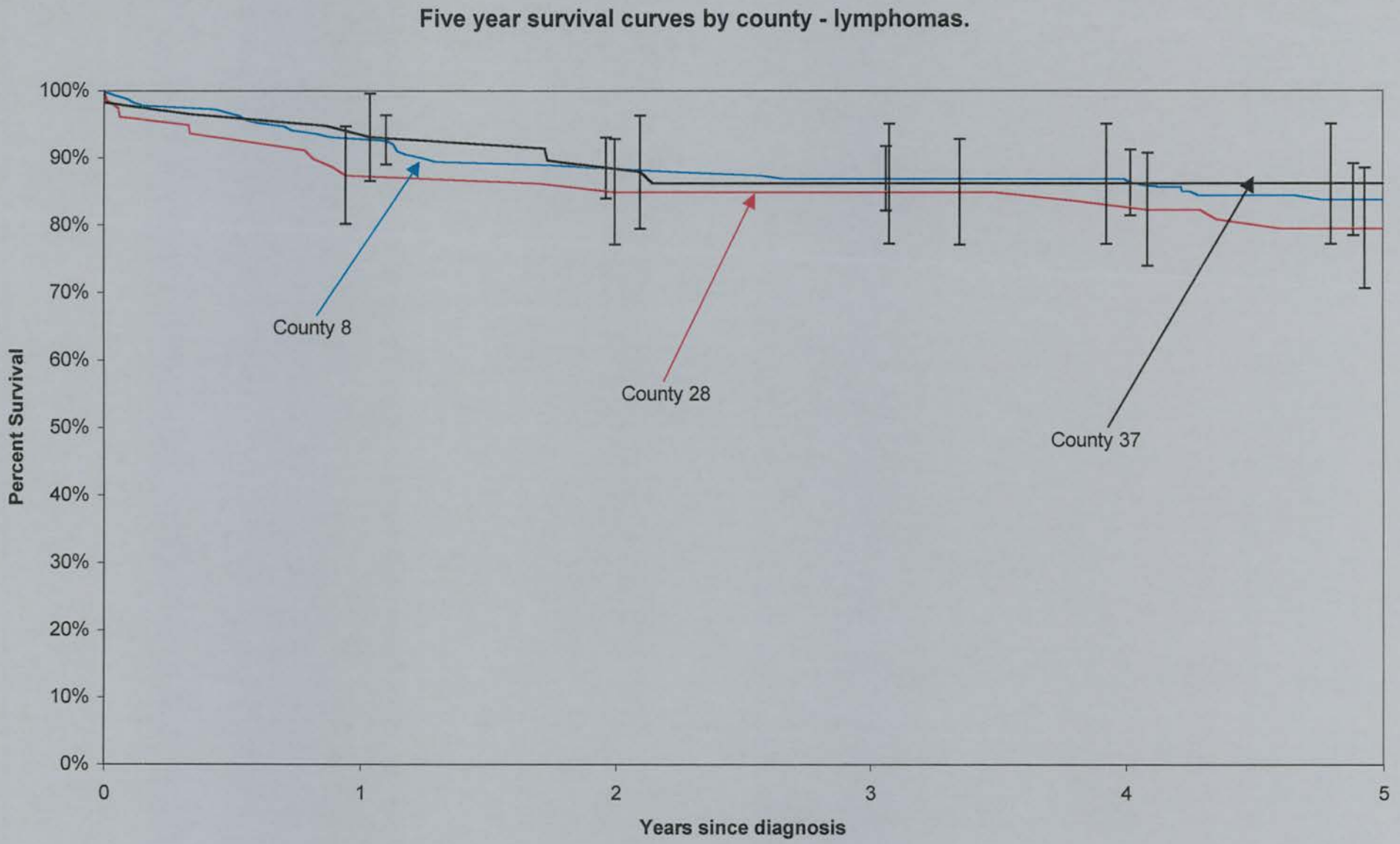

Five year survival curves by county - lymphomas.
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
Percent Survival
0
1
2
3
4
5
Years since diagnosis
County 8
County 28
County 37

Figure 7.42

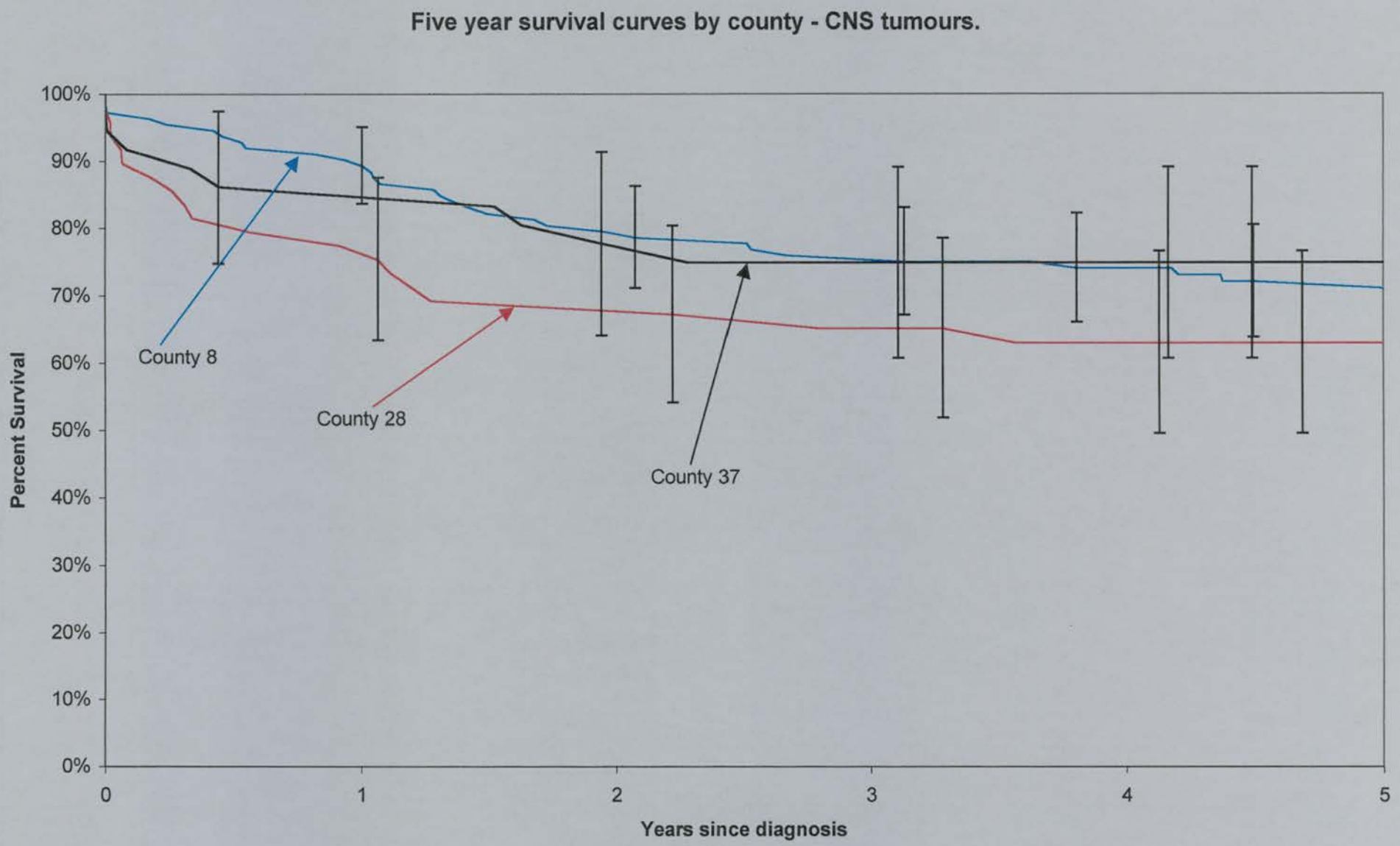

Five year survival curves by county - CNS tumours.
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
Percent Survival
County 8
County 28
County 37
0
1
2
3
4
5
Years since diagnosis

Figure 7.43

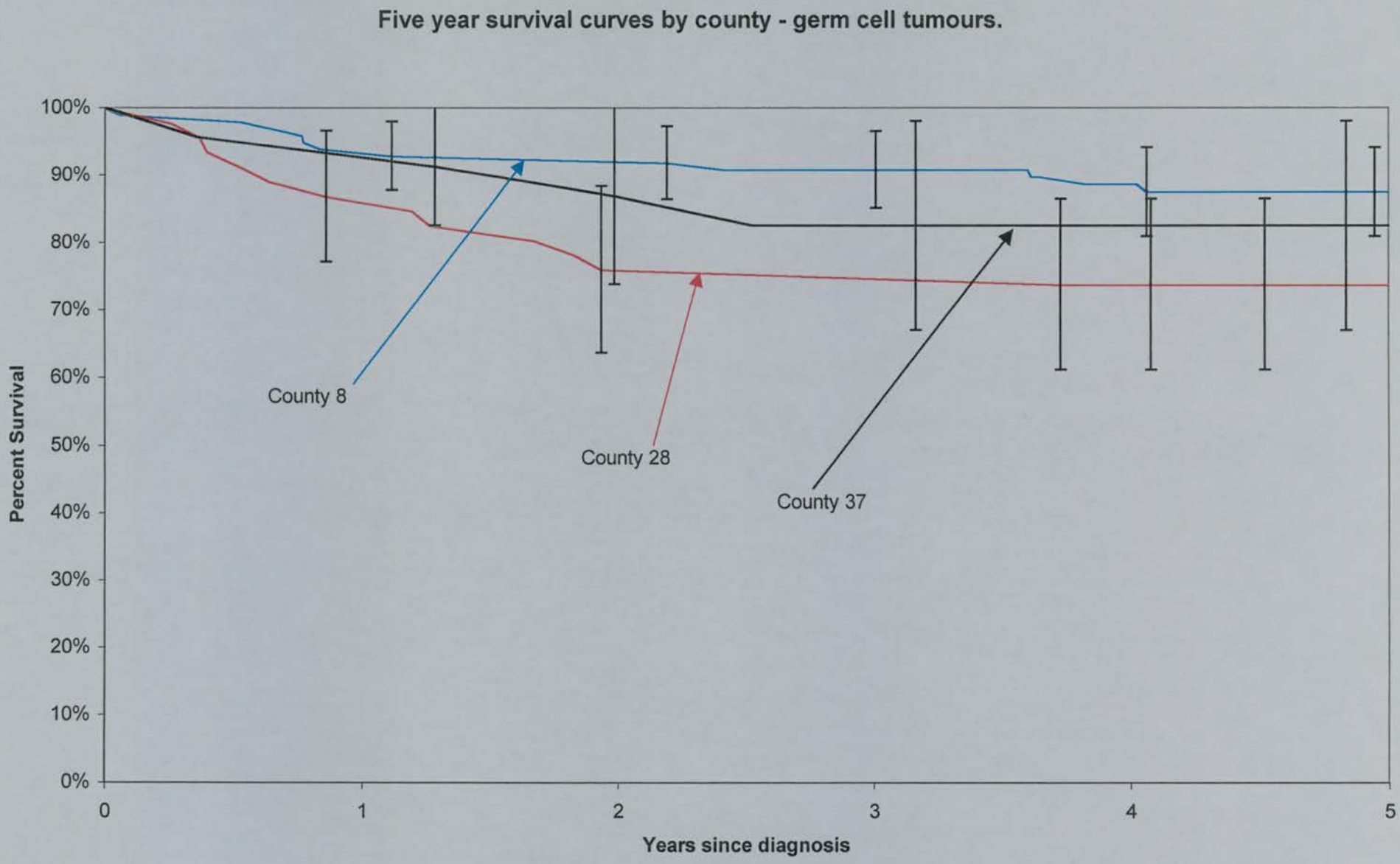
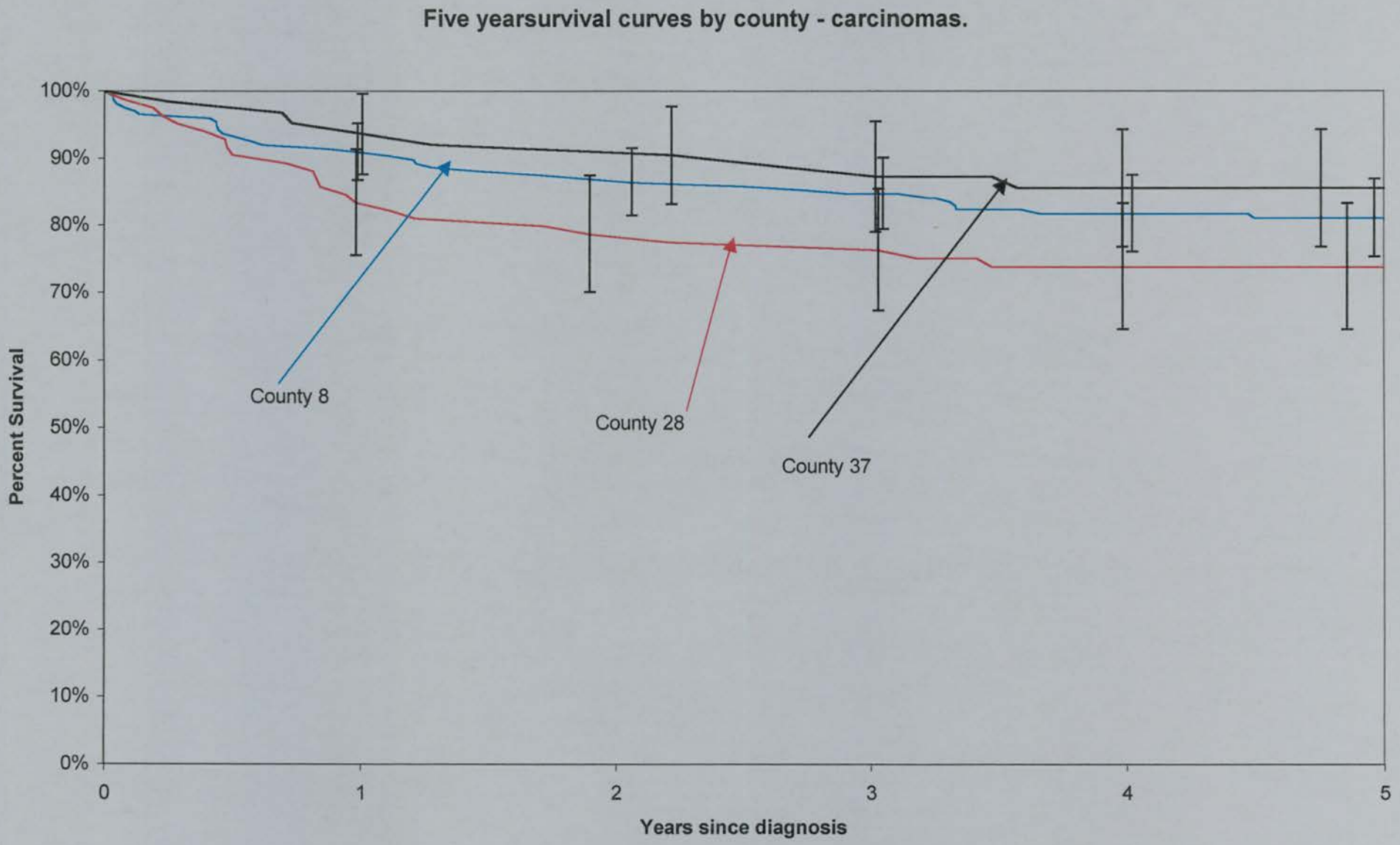

Five year survival curves by county - germ cell tumours.
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
Percent Survival
0
1
2
3
4
5
Years since diagnosis
County 8
County 28
County 37

Figure 7.44


Five yearsurvival curves by county - carcinomas.
100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
Percent Survival
County 8
County 28
County 37
0
1
2
3
4
5
Years since diagnosis

Further examination of the data was performed to determine if it could be demonstrated whether survival had improved over the ten-year period, information requested by consultant staff in Humberside. The following survival curves suggest that survival has if anything got worse, although the changes do not reach statistical significance. Figure 7.45 shows the overall survival curve from 1985-1994. Figure 7.46 shows the survival curve for the first five years of this time period and 7.47 shows the latter (1990-1994). The Humberside line in figure 7.47 is further away from those of North and West Yorkshire suggesting that survival has worsened during this time.

7.5.8.13 Population density

The following table (7.31) shows that population density does not explain the demonstrated differences between survival across Yorkshire.

Table 7.31 Trends in survival by person-based population density and diagnostic group.

		Population density (1=low, 2=medium, 3=high)			**Test of trend**
		% of cases that died			
Diagnostic Group	Cases	Low	Medium	High	P-value
All cancers	1097	23.8	25.9	29.4	0.14
Leukaemias	84	54.6	77.8	57.1	0.35
Hodgkin's disease (HD)	206	12.1	12.9	12.7	0.99
Non-Hodgkin's lymphoma (NHL)	70	28.6	20.0	40.9	0.26
Central nervous system (CNS) tumours	129	29.6	27.9	42.9	0.17
Germ cell tumours	162	13.6	19.3	17.4	0.66
Carcinomas	295	15.9	21.1	23.2	0.44

Figure 7.45 Overall Survival estimates (1985-1994)

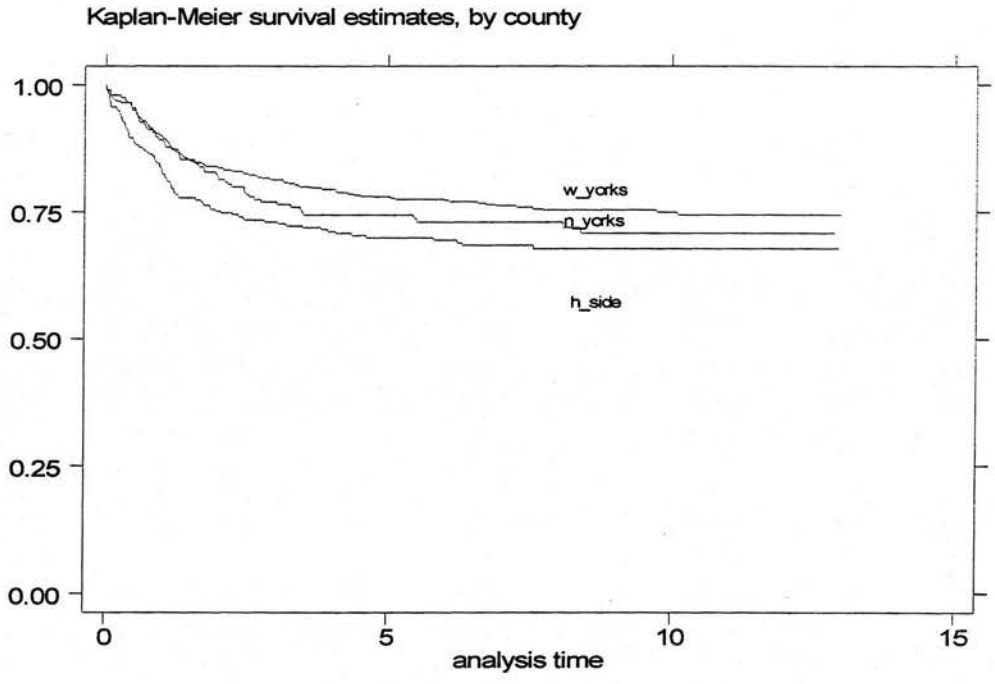


Figure 7.46 Survival estimates (1989-1994)

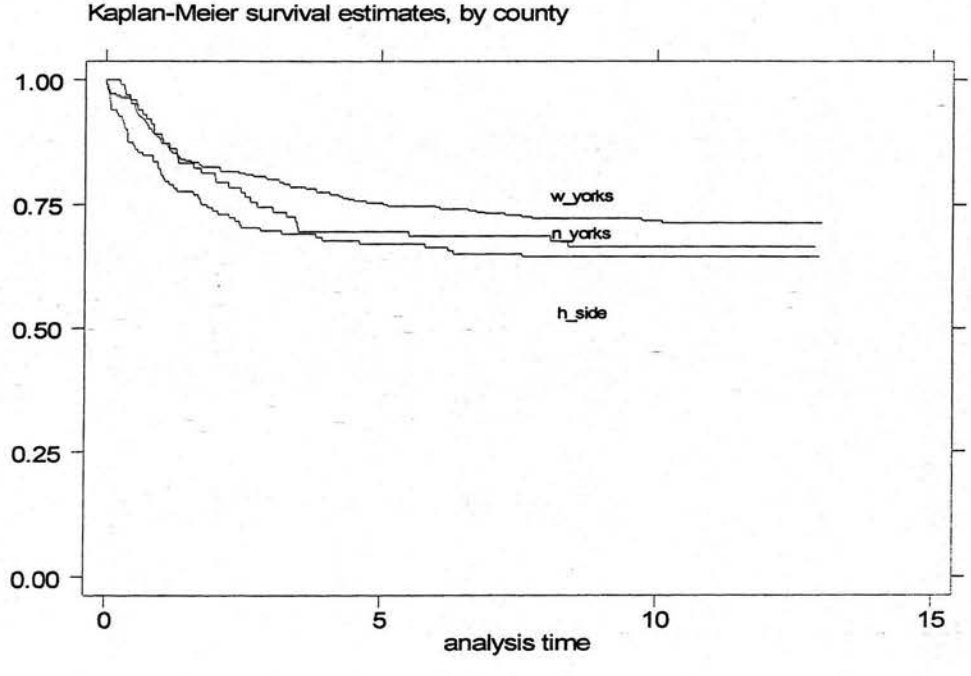
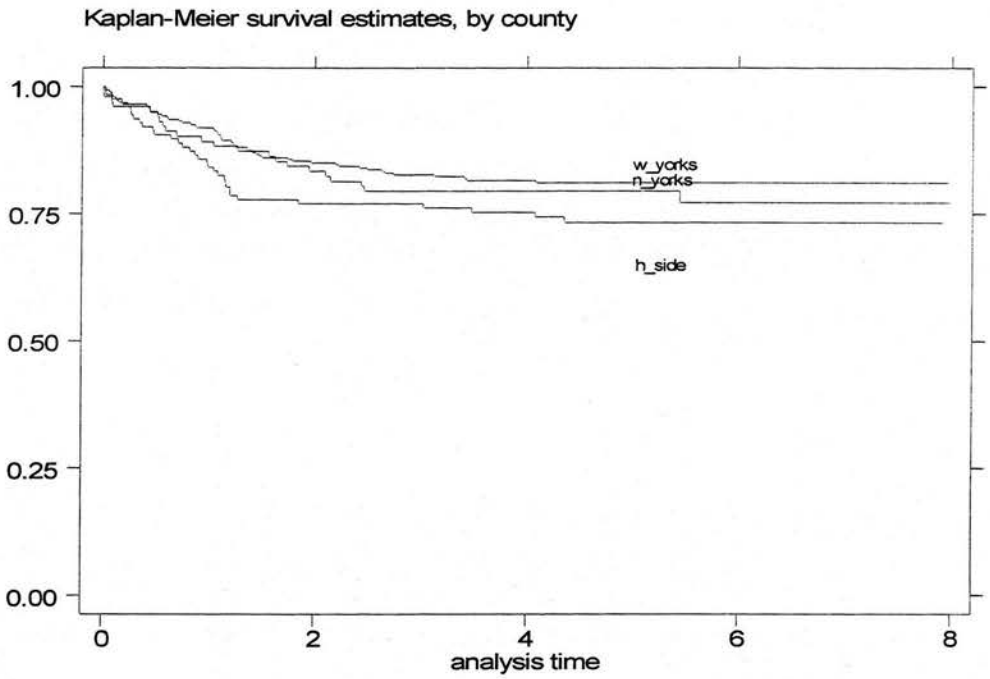


Figure 7.47 Survival estimates (1989-1994)



7.5.9 Survival Results - Hazards Ratio Method

Table 7.32 Frequency of cancers and number of deaths by diagnostic group

Diagnostic group		cases	deaths	%
All cancers		1330	358	26.9
Leukaemias		136	72	52.9
Lymphomas				
	Hodgkin's Lymphoma	224	27	12.1
	Non-Hodgkin's Lymphoma	95	29	30.5
CNS Tumours		192	57	29.7
Germ Cell Tumours		167	28	16.8
Carcinomas		310	64	20.6

Of the 1375 in the original data set, 45 patients were omitted because of the potential unreliable completion of death data for the years 1996 - 1997. This represented 0.032% of cases (table 7.29).

Table 7.33 is the summary table of results from multi-variate analysis of survival with table 7.34 showing the numbers of events in each category (table 7.33a shows the 95% confidence limits of the figures shown in table 7.33) Within this series, 358 deaths were recorded. The total number of person years of survival to censor dates was 8,400.7 years. Length of follow-up arranged from 0 days to 9.9 years. Kaplan-Meier survival curves are shown for all categories of tumour, as well as the revised groupings.

7.5.9.1 Results - General observations

No significant difference between males and females were identified. Young female adults with carcinomas, leukaemias, and all cancers, appeared to do better than their male counter-parts. However, they would appear to do worse

Table 7.33 Hazard Ratios (HR) of dying using multivariate Cox regression modelling by diagnostic group for sex, age, socioeconomic status. place of residence, treatment and other variables.

Variable	All cancers	Leukaemia	ALL*	AML**	Hodgkin's Disease	Non Hodgkin's Lymphoma	CNS Tumours***	Germ Cell Tumours	Carcinomas
10-24 year olds									
Sex									
male	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
female	0.87	0.72	0.72	0.65	1.18	2.24	0.99	2.00	***0.56***
Age at diagnosis									
10-14	1.03	***0.31***	***0.29***	0.79	0.25	1.50	0.55	0.86	0.77
15-19	0.99	***0.50***	0.75	0.29	1.08	1.23	0.77	0.58	0.65
20-24	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
Period of diagnosis									
1985-1989	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
1990-1994	***0.73***	1.05	0.82	0.50	0.68	***0.39***	1.03	0.44	0.65
County of residence									
West Yorkshire	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
Humberside	***1.54***	1.93	2.58	1.95	1.28	0.77	1.40	***2.87***	1.33
North Yorkshire	***1.41***	1.91	***3.29***	2.33	0.34	1.43	0.99	1.28	1.04
Carstairs index									
1-most affluent	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
2	***1.21***	2.02	1.04	3.88	0.92	0.75	1.05	2.28	2.31
3	0.67	0.60	0.28	0.32	0.77	0.33	1.18	0.68	1.41
4	0.81	1.16	0.20	2.79	0.67	0.29	0.82	1.54	2.75
5	1.02	1.59	0.97	1.89	1.03	0.39	0.93	0.73	2.70
test for trend (P=)	0.72	0.80	0.62	0.89	0.92	0.23	0.82	0.61	0.11
Size of treating hospital									
Large	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
Medium	0.89	0.85	2.49	0.78	0.34	2.06	1.31	4.02	1.03
Small	0.86	0.67	0.65	0.69	0.61	1.14	0.83	4.14	1.22
Treatment									
chemotherapy given		1.00	1.00	1.00					
chemotherapy not given		***3.78***	0.89	***7.48***					
Population density									
low	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
medium	***1.39***	***2.20***	***3.64***	0.77	0.82	1.09	1.20	***3.06***	0.95
high	***1.55***	1.14	1.90	0.32	0.84	3.26	1.53	1.79	1.07

figures in bold = p<0.05

*Acute lymphoblastic leukaemia
**Acute myeloid leukaemia
***Central Nervous System

Table 7.33a

95% Confidence Limits of Hazard Ratios (HR) shown in table 7.33

Variable		All cancers	Leukaemias	ALL	AML	Hodgkin's Disease	Non Hodgkins Lymphoma	CNS Tumours	Germ Cell Tumours	Carcinomas
10-24 year olds										
Sex										
	male	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
	female	0.70-1.07	0.43-1.19	0.32-1.67	0.25-1.72	0.54-2.56	0.95-5.33	0.57-1.69	0.81-4.96	0.33-0.93
Age at diagnosis										
	10-14	0.77-1.37	0.17-0.59	0.09-0.88	0.08-1.01	0.03-2.00	0.51-4.43	0.29-1.05	0.09-7.82	0.27-2.21
	15-19	0.78-1.26	0.28-0.89	0.28-1.99	0.19-3.30	0.48-2.43	0.49-3.08	0.39-1.51	0.21-1.63	0.34-1.24
	20-24	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
Period of diagnosis										
	1985-1989	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
	1990-1994	0.58-0.90	0.63-1.75	0.36-1.86	0.17-1.46	0.29-1.60	0.16-0.95	0.59-1.79	0.19-1.02	0.39-1.09
County of residence										
	West Yorkshire	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
	Humberside	1.16-2.02	0.97-3.81	0.98-8.34	0.53-7.16	0.45-3.67	0.27-2.18	0.68-2.90	1.06-7.78	0.71-2.50
	North Yorkshire	1.02-1.93	0.97-3.77	1.17-9.20	0.52-10.51	0.67-1.74	0.38-5.39	0.44-2.24	0.32-5.10	0.47-2.31
Carstairs index										
	1-most affluent	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
	2	0.85-1.69	0.91-4.49	0.32-3.42	0.74-20.26	0.25-3.41	0.19-3.04	0.434-2.49	0.62-8.40	0.86-6.25
	3	0.45-0.99	0.24-1.49	0.07-1.11	0.05-2.14	0.20-3.00	0.07-1.58	0.43-3.27	0.16-2.82	0.46-4.29
	4	0.53-1.24	0.45-3.03	0.03-1.45	0.54-14.27	0.14-3.31	0.05-1.75	0.25-2.66	0.35-6.78	0.87-8.63
	5	0.65-1.59	0.63-4.04	0.22-4.69	0.29-12.31	0.20-5.39	0.07-2.18	0.27-3.26	0.13-4.02	0.83-8.82
Size of treating hospital										
	Large	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
	Medium	0.67-1.19	0.38-1.90	0.62-9.97	0.19-3.23	0.99-1.16	0.73-5.82	0.67-2.56	0.77-21.05	0.49-2.14
	Small	0.64-1.13	0.31-1.46	0.18-2.40	0.15-3.29	0.22-1.75	0.37-3.49	0.23-3.03	0.85-20.20	0.57-2.60
Treatment										
	chemotherapy given		1.00	1.00	1.00					
	chemotherapy not given		1.69-8.45	0.15-5.29	1.96-28.43					
Population density										
	low	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
	medium	1.02-1.89	1.00-4.83	1.05-12.56	3.52	0.25-2.61	0.32-3.78	0.55-2.60	1.09-8.53	0.46-2.04
	high	1.05-2.28	0.45-2.90	0.34-10.67	0.87	0.18-4.00	0.85-12.49	0.55-4.27	0.51-6.30	0.41-2.77

Table 7.34

Numbers of patients in each category

Variable	All cancers	Leukaemia	ALL*	AML**	Hodgkin's Disease	Non Hodgkin's Lymphoma	CNS Tumours***	Germ Cell Tumours	Carcinomas
10-24 year olds									
Sex									
male	682	72	43	19	117	62	106	132	93
female	666	64	35	28	110	33	89	36	226
Age at diagnosis									
10-14	251	52	35	13	21	25	66	6	24
15-19	408	44	32	11	85	39	53	44	74
20-24	689	40	11	23	121	31	76	118	221
Period of diagnosis									
1985-1989	699	67	42	19	120	48	98	91	155
1990-1994	649	69	36	28	107	47	97	77	164
County of residence									
West Yorkshire	766	76	44	25	135	52	111	99	174
Humberside	333	33	19	11	55	22	48	46	83
North Yorkshire	249	27	15	11	37	21	36	23	62
Carstairs index									
1-most affluent	279	22	13	8	46	24	48	37	55
2	256	27	16	9	41	13	44	26	61
3	269	29	20	7	46	15	31	39	78
4	271	30	13	16	51	16	38	37	57
5	273	22	16	7	43	27	34	29	68
Size of treating hospital									
Large	513	96	57	34	73	38	94	47	75
Medium	362	15	7	6	56	26	86	38	100
Small	461	25	14	7	98	31	13	82	136
Chemotherapy									
Yes		122	73	40					
No		14	5	7					
Population density									
Low	447	34	22	11	72	35	72	64	97
Medium	452	49	27	18	91	24	57	56	107
High	449	53	29	18	64	36	66	48	115

*Acute lymphoblastic leukaemia
**Acute myeloid leukaemia
***Central Nervous System

with germ cell tumours, Hodgkin's Disease and non-Hodgkin's Disease. Some of the differences shown in the hazard ratio calculations are quite large and plausibility of the size of these differences must be raised. Although technically statistically significant, some of the numbers in the subgroups are relatively small and therefore these observations should be interpreted with caution.

7.5.9.2 Age at Diagnosis

The data suggested that the younger the patient with cancer the more likely they were to survive, although the differences were not significant overall. Significant improvements in survival were observed in the 10 - 14 year age group for leukaemia's and CNS tumours, and in the 15 - 19 year olds with germ cell tumours. It can be seen that the ratio of the incidence of ALL:AML changes from a predominance of ALL in younger age groups to that of AML in 20-24 year olds.

7.5.9.3 Period of Diagnosis

Significant improvements in survival have been observed during the second 5-year period of study. The improvements were significant in non-Hodgkin's Disease.

7.5.9.4 County of Residence

The most striking feature of the data is the consistent increased risk of death in Humberside and North Yorkshire compared with West Yorkshire across most diagnostic groups. This is not explained by socio-economic status or population

density. The overall significant increase of death of 54% in Humberside and 41% in North Yorkshire is reflected most strongly in adolescents with leukaemia: here, the risk of death in North Yorkshire and Humberside is almost twice as great. Some larger differences are seen in ALL.

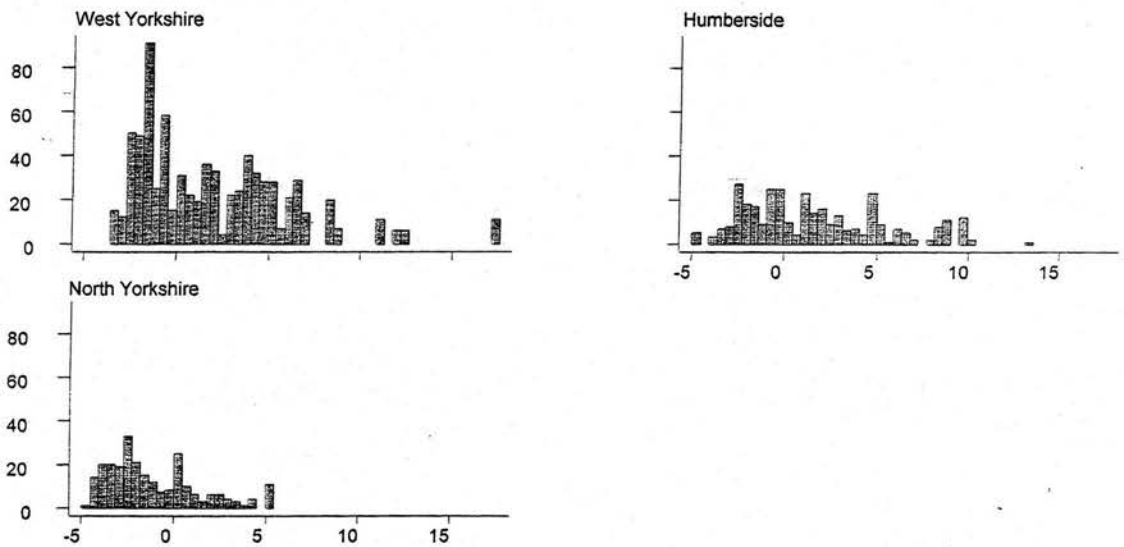
7.5.9.5 Socio-economic disadvantage

For socio-economic status and survival a non-significant dose response was present in the carcinoma group and came close to, but did not reach, statistical significance. Those in the least affluent groups were at least twice as likely to die compared to the most affluent. Numbers of deaths were insufficient to sub-categorise this heterogeneous group of malignancies.

The figure below shows the distribution of scores from the Carstairs index for each of the main county areas. It suggests that there are a greater proportion of deprived wards in West Yorkshire than in either North or East Yorkshire. This again suggests that the observed differences are not due to social disadvantage.

Figure 7.48 Illustrates histograms showing the frequency Carstairs scores (measures of disadvantage) in wards in each of the counties under consideration

(negative – most deprived; positive – least deprived)



Histograms by county

7.5.9.6 Size of treating hospital and Treatment

The picture was mixed. No significant differences were observed. The difficulties in labelling a particular treatment episode according to hospital size means interpretation of these data are problematic.

Receiving chemotherapy in leukaemia is an indicator of significant survival benefit especially in AML. Similarly, treatment of germ cell tumours by surgery produces a similar effect.

7.5.9.7 Population Density

The data suggests that greater population density is associated with poorer survival.

7.5.9.8 Analysis with the 10-14 year olds removed

As the service issue is predominantly about the health care of the older age groups in this study (i.e. 15 – 24), then in order to look in more detail at these age groups the effect of the age group 10-14 had been removed. These analyses are shown in tables 7.35 –7.36. (Confidence limits are shown in table 7.35a). This then exacerbates the differences especially in survival of AML and ALL in the county analyses.

Table 7.35

Hazard Ratios (HR) of dying using multivariate Cox regression modelling by diagnostic group for sex, age, socioeconomic status. place of residence, treatment and other variables.

Variable	All cancers	Leukaemia	ALL*	AML**	Hodgkin's Disease	Non Hodgkins Lymphoma	CNS Tumours***	Germ Cell Tumours	Carcinomas
15-24 year olds									
Sex									
male	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
female	0.91	**0.52**	***0.24***	0.47	1.06	***6.45***	1.03	2.12	***0.57***
Age at diagnosis									
15-19	1.01	**0.45**	1.10	0.15	1.09	1.63	0.79	0.67	0.66
20-24	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
Period of diagnosis									
1985-1989	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
1990-1994	***0.70***	1.15	0.57	0.67	0.61	***0.27***	0.91	0.45	0.68
County of residence									
West Yorkshire	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
Humberside	***1.47***	***2.53***	***13.31***	1.40	1.34	2.06	1.12	***3.50***	1.38
North Yorkshire	1.39	***2.39***	***5.78***	2.48	0.35	4.37	0.77	1.91	1.05
Carstairs index									
1-most affluent	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
2	1.14	1.82	0.35	***80.47***	0.91	0.95	0.79	3.43	1.57
3	0.65	0.75	***0.14***	2.74	0.84	0.30	0.87	0.64	1.15
4	0.80	1.48	0.11	12.46	0.84	0.47	0.35	2.56	2.12
5	0.95	2.08	1.33	5.18	0.96	0.85	0.46	1.01	2.02
Test for trend (p=)	0.56	0.44	0.96	0.77	0.93	0.77	0.23	0.61	0.21
Size of treating hospital									
Large	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
Medium	0.98	0.73	4.73	0.19	0.34	4.15	1.89	7.53	0.88
Small	0.93	0.68	0.82	0.95	0.58	1.28	1.05	***8.49***	1.09
Treatment									
chemotherapy given		1.00	1.00	1.00					
chemotherapy not given		***4.82***	0.57	***5.00***					
Population density									
low	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
medium	1.35	2.00	3.52	10.34	0.73	1.32	1.36	***3.94***	1.19
high	***1.56***	0.77	0.87	1.34	0.73	5.33	2.76	1.78	1.20

figures in bold p<0.05

*Acute lymphoblastic leukaemia
**Acute myeloid leukaemia
***Central Nervous System

Table 7.35a

95% Confidence Limits of Hazard Ratios (HR) shown in table 7.35

Variable	All cancers	Leukaemias	ALL	AML	Hodgkin's Disease	Non Hodgkins Lymphoma	CNS Tumours	Germ Cell Tumours	Carcinomas
15-24 year olds									
Sex									
male	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
female	0.72-1.15	0.27-0.99	0.08-0.71	0.87-2.57	0.48-2.34	2.12-19.60	0.54-1.95	0.81-5.58	0.33-0.97
Age at diagnosis									
15-19	0.79-1.28	0.25-0.82	0.37-3.36	0.22-1.07	0.48-2.47	0.57-4.64	0.40-1.57	0.27-1.92	0.35-1.25
20-24	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
Period of diagnosis									
1985-1989	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
1990-1994	0.55-0.89	0.63-2.07	0.18-1.82	0.17-2.60	0.25-1.49	0.08-0.93	0.47-1.79	0.19-1.07	0.40-1.17
County of residence									
West Yorkshire	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
Humberside	1.08-1.99	1.12-5.71	2.5-70.45	0.29-6.78	0.47-3.78	0.53-8.10	0.48-2.61	1.24-9.84	0.72-2.62
North Yorkshire	0.97-2.00	1.07-5.30	1.47-22.7	0.51-12.03	0.07-1.79	0.63-30.37	0.27-2.23	0.50-7.21	0.45-2.43
Carstairs index									
1-most affluent	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
2	0.78-1.65	0.65-5.09	0.07-1.69	1.83-3527.21	0.25-3.30	0.19-4.63	0.28-2.20	0.86-13.74	0.57-4.29
3	0.42-1.00	0.28-2.07	0.02-0.78	0.10-74.50	0.21-3.40	0.37-2.37	0.27-2.82	0.13-3.24	0.37-3.58
4	0.500-1.27	0.45-4.89	0.01-1.33	0.51-307.09	0.17-4.08	0.64-3.44	0.87-1.44	0.54-12.26	0.67-6.63
5	0.59-1.53	0.69-6.29	0.20-8.97	0.30-90.04	0.17-5.23	0.93-7.75	0.11-1.95	0.17-6.14	0.63-6.50
Size of treating hospital									
Large	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
Medium	0.71-1.36	0.31-1.77	0.85-26.32	0.22-1.67	0.99-1.15	0.96-17.92	0.85-4.16	0.86-65.89	0.41-1.89
Small	0.67-1.27	0.30-1.55	0.18-3.77	0.22-4.10	0.20-1.64	0.32-5.18	0.22-5.10	1.02-70.93	0.51-2.37
Treatment									
chemotherapy given	1.00	1.00	1.00	1.00					
chemotherapy not given	0.19-3.16	2.04-11.42	0.66-4.82	1.20-20.80					
Population density									
low	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
medium	0.96-1.90	0.85-4.67	1.05-12.56	0.91-117.69	0.23-2.36	0.30-5.81	0.54-3.40	1.32-11.78	0.54-2.62
high	1.02-2.39	0.30-1.96	0.34-10.67	010-18.40	0.15-3.60	0.92-30.74	0.87-8.81	0.51-6.15	0.46-3.11

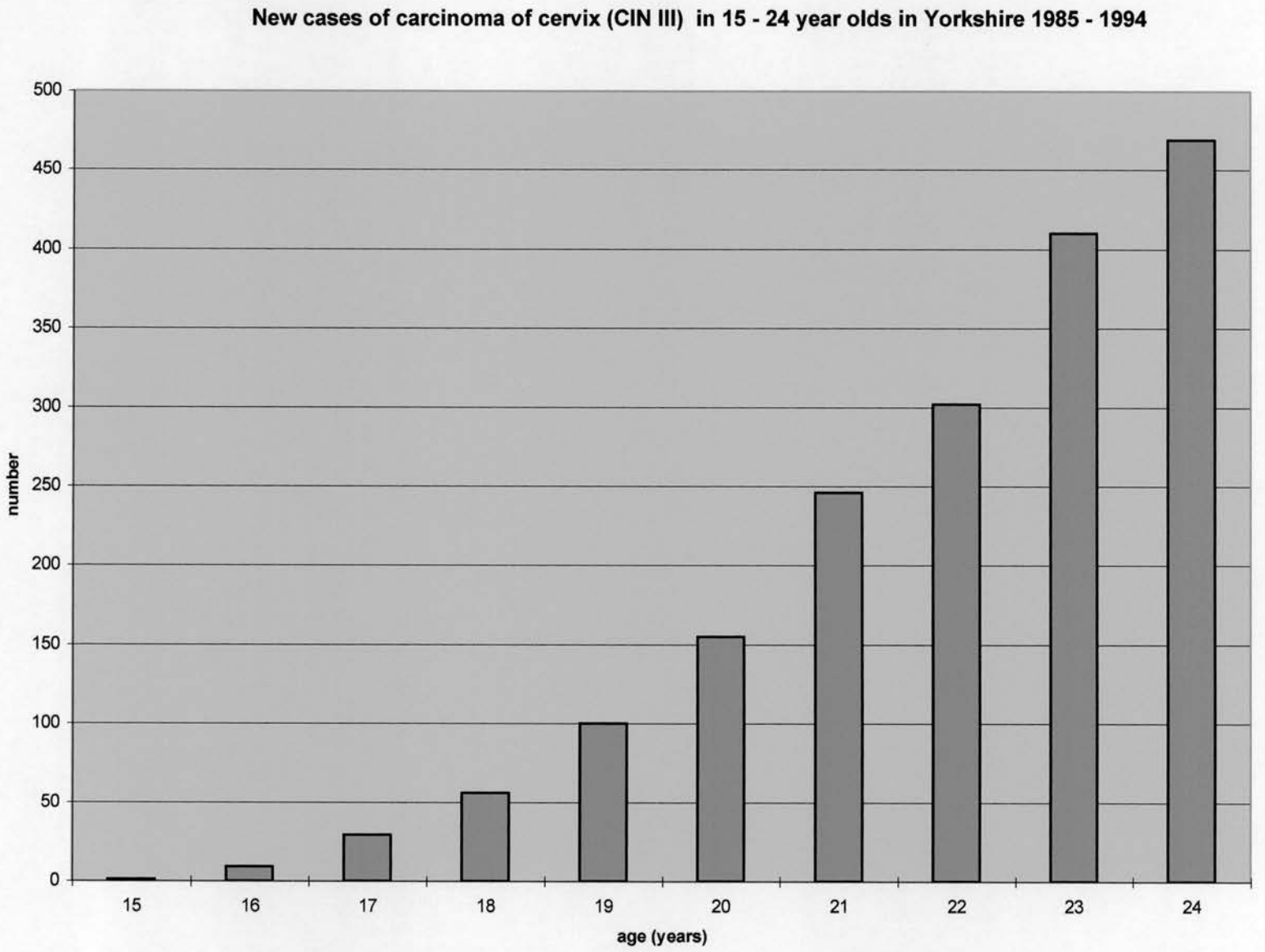
Table 7.36

Numbers of patients in each category

Variable	All cancers	Leukaemia	ALL*	AML**	Hodgkin's Disease	Non Hodgkin's Lymphoma	CNS Tumours***	Germ Cell Tumours	Carcinomas
15-24 year olds									
Sex									
male	539	45	25	14	102	45	69	130	83
female	558	39	18	20	104	25	60	32	212
Age at diagnosis									
15-19	408	44	32	11	85	39	53	44	74
20-24	689	40	11	23	121	31	76	118	221
Period of diagnosis									
1985-1989	575	43	25	15	110	38	66	88	144
1990-1994	522	41	18	19	96	32	63	74	151
County of residence									
West Yorkshire	615	41	22	15	117	35	78	98	161
Humberside	278	23	12	9	52	16	31	45	78
North Yorkshire	204	20	9	10	37	19	20	19	56
Carstairs index									
1-most affluent	220	11	6	4	43	19	25	33	47
2	216	16	9	6	40	12	33	28	61
3	219	22	14	6	42	11	19	36	68
4	215	16	5	11	41	12	27	36	53
5 - least affluent	227	19	9	7	40	16	25	29	66
Size of treating hospital									
Large	351	50	26	22	57	23	64	44	68
Medium	314	14	7	5	55	21	55	387	91
Small	420	20	10	7	94	16	8	79	128
Treatment									
chemotherapy given		72	40	27					
chemotherapy not given		12	3	7					
Population density									
Low	366	22	13	8	66	28	44	59	88
Medium	367	27	13	12	85	20	43	57	95
High	364	35	17	14	55	22	42	46	112

*Acute lymphoblastic leukaemia
**Acute myeloid leukaemia
***Central Nervous System

Figure 7.49


New cases of carcinoma of cervix (CIN III) in 15 - 24 year olds in Yorkshire 1985 - 1994
number
500
450
400
350
300
250
200
150
100
50
0
15
16
17
18
19
20
21
22
23
24
age (years)

7.6 Individual cancer requiring special comment

7.6.1 Cancer of the cervix

The distribution of CIN III by age is shown in table 7.37 and illustrated in figure 7.49 and demonstrates the rapid rise in incidence with age.

Table 7.37 Number of Cases of CIN III recorded 1985-1994 in Yorkshire

age	Total number of cases of CIN III
15	1
16	9
17	29
18	56
19	100
20	155
21	246
22	302
23	410
24	469
Grand Total	1777

In the Yorkshire region, between 1985 1994, there were a total of 88 hydatidiform moles, with the majority occurring at the age of 20 years.

Table 7.38 shows the age distribution of patients with the tumour.

Table 7.38 Age distribution of cases of hydatidiform mole in Yorkshire 1985 - 1994

Age	Number of Cases
15	3
16	3
17	10
18	7
19	9
20	17
21	13
22	6
23	10
24	10
Total	88

This is a relatively uncommon tumour, but with few causing significant long term problems for patients.

7.7 Disease Management

The following table illustrates where patients aged 10-24 years old, during the study period were treated in both the Northern and Yorkshire part of the region.

Table 7.39 Place of treatment of people aged 10-24 with cancer

Place of treatment		**Northern**				**Yorkshire**			
Age band		10-14	15-19	20-24	total	10-14	15-19	20-24	total
Major cancer centre	n	163	211	266	640	212	244	402	858
	%	87.63	63.36	51.45	61.78	83.14	58.51	57.18	62.40
Other cancer centre	n	16	45	74	135	17	62	110	189
	%	8.60	13.51	14.31	13.03	6.67	14.87	15.65	13.75
Other hospital	n	7	77	177	261	26	111	191	328
	%	3.76	23.12	34.24	25.19	10.20	26.62	27.17	23.85
Total	n	186	333	517	1036	255	417	703	1375
	%	100	100	100	100	100	100	100	100

7.8 Results of the Qualitative Study

7.8.1 Healthy adolescent focus group

This focus group took place at a school some 50 miles away from the nearest cancer centre. There were four males and four females in the group. All were Caucasian. All members of the group had 10 GCSEs, all claimed to be fit and well. Only two members of the group had *never* been admitted to hospital. The commonest reason for hospital admission was trauma. Most of the group was

from social class IIIM and above, only one child in the group was from below social class III. The discussion lasted 80 minutes, and was fitted into a standard teaching period. The group displayed a good understanding of cancer, this may have been helped by the fact that a pupil in the school had recently been diagnosed with cancer.

When asked to prioritise a list of issues deemed to be important, these were ranked and are shown in the box below:

Box 7.1 Rankings of criteria deemed to be important in healthy adolescents

1. Getting better
2. Being managed in a specialist centre
3. Being accessible for parents
4. Being accessible for friends
5. Being close to home
6. Keeping up with education

Some of the quotes from pupils are shown below in boxes:

"Well I was stuck in this little room because was the oldest in a children's ward. It was last year and they wouldn't put me in an adult ward and I had nothing to do....."

There were lots of little kids running round!

"(adult wards)..are just full of old men having hips replaced and stuff"

There was strong support for being looked after in an adolescent cancer centre, being in a centre of excellence; being in an appropriate environment was felt to be very important.

You're with people who've got the same problem as you.

.....You can discuss it with them

"cancer is more focussed and if you've got cancer you're in a specialist centre anyway, so you're going to have more of your own age and then you would be in a ward with your own age"

Those who had been admitted to hospital felt that being looked after in a dedicated environment for teenagers was very important. There were examples of dissatisfaction of care in both paediatric and adult wards.

(Where you would like to be looked after)....Not like a hospital, not like wards with loads of beds in . Just like the surroundings similar to what you normally have.

7.8.2 Results of the focus group of professionals in a setting away from the cancer centre

A focus group lasting for one hour was held in a unit away from the cancer centre. The participants were three consultant paediatricians, one of whom had special experience in the management of cancer. The main conclusions from

the focus group was that there was strong support for the creation of an adolescent cancer centre as long as this was not funded at the expense of peripheral units and would not compromise the current shared care arrangements which were felt to be working very well.

The other themes were as follows:

Access - distance was not felt to be a problem:

> *What you tend to find is that the further you get away from this hospital, the less concerned families become about travelling vast differences. I'm thinking of one family from K****, who were just as happy to drive to Leeds as they were to drive here. There isn't a problem with transport unless the family is poverty stricken and transportless. There are some on Catterick Garrison, and that is a problem.*

Importance of a centre of expertise

> *...these children have three or four drips up, they need a nurse, more than one nurse, and they need a fully trained nurse. A frightening number of nurses here have not got the expertise, neither have the SHOs ..... I think it would be unreasonable to expect our GP trainees to do it.*

..and contact with other teenagers;

> *they get a lot of support from other teenagers and children in the unit and they grow older with them. OK they die, some of them, but they can discuss that and they're not suddenly left in limbo when there are other major changes occurring, like leaving school or going on to college...*

maintaining education and 'being seen to be normal' was felt to be important;

> *they don't want to miss school at this stage. They don't want to be different*

Agreeing an appropriate level of shared care was felt to be important;

> *I think with teenagers coming up for exams, they can come for a review, have a finger prick and be back at school by ten. They go down to Leeds and it's the whole morning and you know we can always negotiate....*
>
> *... I think whatever can be done, should be done on (this) site, the none expert stuff, review of blood counts, occasional treating of febrile neutropaenia, occasional delivery of chemotherapy as laid down by a recipe from the centre*

7.8.3 Results of the focus group and interviews among adolescents with cancer

A total of fourteen young patients were interviewed. Two groups of three were run and eight further adolescents were interviewed individually. The interviews lasted between 45 minutes and 1 hour each. Interviewing in the outpatient department proved much the most successful approach. Many adolescents in the ward were too ill to participate in the focus groups. Individual interviews proved adequate as in the groups that were run, the small numbers involved in each meant there was little opportunity to develop themes in the way that can normally be expected from focus groups.

The demographic details of the patients are shown in table 7.40 below, and where they were treated (table 7.41):

Table 7.40 Demographic profile of focus group participants

Patient No	Age	Sex	Diagnosis	GCSE	Father's occupation	Mother's occupation	Ethnic group
1	16	Male	Hodgkin's Disease	0	Manager	None	Caucasian
2	18	Female	Ewing's Sarcoma	8	Metal worker	Carer	Caucasian
3	19	Male	Rhabdomyosarcoma	9	None	Hoffman presser	Caucasian
4	18	Male	Rhabdomyosarcoma	7	Mechanic	Housewife	Asian
5	16	Male	Osteosarcoma	0	None	None	Asian
6	15	Female	PNET[13]	0	Opera singer	Singing teacher	Caucasian
7	20	Male	Osteosarcoma	11	Lecturer	Teacher	Caucasian
8	17	Female	Osteosarcoma	6	Retired	Housewife	Caucasian
9	16	Male	Hodgkin's Disease	9	Fireman	Secretary	Caucasian
10	13	Male	Soft tissue sarcoma	0	Trainer	Nurse	Caucasian
11	15	Male	ALL	0	Unemployed	Unemployed	Caucasian
12	16	Male	ALL	0	-	Unemployed	Caucasian
13	16	Female	ALL	0	Storeman	Care worker	Caucasian
14	18	Male	Hodgkin's Disease	8	Factory manager	Staff nurse	Caucasian

Table 7.41 Place of treatment of patients in qualitative study

Patient No	Hospital 1	Hospital 2	Hospital 3
1	Dewsbury	St James, Leeds	
2	St James, Leeds	Airedale	
3	Leeds General	St James, Leeds	
4	Bradford Royal	Cookridge	St James, Leeds
5	Birmingham	St James, Leeds	
6	Bradford Royal	Leeds General	St James, Leeds
7	York	Birmingham	St James, Leeds
8	St James, Leeds	Birmingham	
9	Bradford Royal	St James, Leeds	
10	Hull Royal	St James, Leeds	
11	St James, Leeds		
12	St James, Leeds	Leeds General	
13	St James, Leeds		
14	St James, Leeds		

[13] Primitive Neuro-ectodermal tumour

The main themes to emerge were as follows:

1. There were recurrent problems of delays in diagnosis. This did not appear to be the case with the leukaemic patients who by and large experienced speedy diagnosis and referral for treatment. Some adolescents reported prolonged delays in diagnosis with a minimum period of three weeks and in one case up to seven months. Presentations were generally atypical, and in some instances patients were only admitted after repeated presentation at an accident and emergency department. There were some significant delays on occasions within general hospitals as well as in primary care. There was an underlying feeling that there had been undue delay in their diagnoses. In some cases this had led to considerable resentment towards the referring hospitals and their doctors.

*I was on children's ward and every single doctor in D****** Hospital saw me, every one. I had about five trainees as well. I had about seven main doctors, who came to se me, none of them knew what it was and then they set the trainees on to me as well!*

I saw my doctor at home and he said it was just a swelling. I went again and they sent me home again.

2. Once the patients were in contact with the adolescent ward, the care was deemed to be excellent. They felt that they wanted to be told straight as had always occurred in the specialist unit.

Its got a lot of facilities and this is the best place to be really. If you had to pick somewhere, I'd pick here.

The staff in this unit are really nice.

3. Education ranked persistently highly among the patients
4. As well as what was perceived to be high quality treatment, being in close proximity to other young people with similar conditions was felt to be of great importance. It was felt to be well worth travelling for specialist treatment

On an adult ward..... I didn't really like it and I kept jumping from ward to ward. I was on an adult ward and this patient who was next to me, was like 25 and then I moved down the ward and I don't think that there was anyone under 50 in the ward

I think this place [adolescent unit] is very good. Its miles better than the children's ward, because they specialise in your type of thing, so you're not alone and everybody there has got what you've got so it gives you a bit of comfort that you can talk to other people who understand, instead of someone who's got a nasty little cold next to you, you've got such a big.....

Box 7.2 Rankings of criteria deemed to be important in adolescents with cancer

1. Getting better
2. Being managed in a specialist centre
3. Keeping up with education
4. Being accessible for parents
5. Being accessible for friends
6. Being close to home

One of the adolescents raised the issue of being punished.

..I have been on the adult ward many times. I didn't like it at all, knowing what the comparison between the adolescent and adult ward. On the adult ward, it felt like I was in solitude or being punished for something I haven't done.

7.8.4 Results of the focus group and interviews among adolescents with leukaemias

Clinical advice was given which suggested that some specific interviews targeted at adolescents with leukaemia would be of value. This indeed proved to be the case. Different themes did emerge, particularly in respect of the early management of the patients. In particular, diagnosis and referral appeared more straightforward and rapid in-patients with leukaemia than with patients with solid tumours. Of the three patients with leukaemia who were interviewed, all had been managed in the main regional centre and had been referred there rapidly.

7.8.5 Results of discussions with parents of patients

Parents were prepared to put up with considerable inconvenience to be close to their children. In some cases this involved staying away from home for very long periods of time which had adverse effects on other family members. Parents were aware that treatment in a number of cases away from the centre had been sub-optimal. Parents were universally satisfied with the treatment in the centre. Some patients did comment on extending the concept of an adolescent inpatient unit to outpatient facilities.

7.8.5 Conclusions

The qualitative work revealed considerable sub-optimal practice within referring units and in some cases from primary care, this did not appear to apply to patients with leukaemia. There were delays in initiating treatment and in identifying the correct diagnosis. There was no criticism of the treatment in the centre by parents or their children. The perceived expertise in the centre was felt to be very important and the adolescents themselves felt that the staff were more attuned to dealing with the needs of adolescents which were different from children and adults. The facilities (computers, televisions) were an important adjunct in their care, but the overall benefit was the quality of the staff in the centralised unit.

Qualitative work does not aim to identify the size of the particular problem or concern but to identify themes. Care also needs to be given to interpreting information from desperately ill patients who inevitably will want to have the maximum faith in what may be their only place of hope. There may also be inappropriate levels of blame cast against others involved in the young peoples' care in an effort to find some reason for their predicament.

The conclusions that can be drawn from the qualitative work are that there were no real disadvantages of centralised care identified and indeed that there were felt to be very many advantages in bringing the care together as is currently the case in the small unit in Leeds. It was only possible to identify some relatively minor features of the adolescents care that might be improved (food and temperature of the wards), although one young man thought security should be increased because computer games kept being stolen.

8 Service Issues

8.1 The Newcastle Adolescent Cancer Unit

The Newcastle Adolescent cancer centre has been in operation for over one year. On two separate occasions the unit was asked to provide data on its experience to date together with a personal approach to the head of the unit. Unfortunately, no data were made available.

8.2 Treating Consultants

The data from the cancer registry enabled the number of patients in the case series treated by any one consultant to be analysed.

Table 8.1

Patients Treated	Number of consultants	%
30+	4	0.81
20-29	6	1.22
10-19	15	3.05
5-9	34	6.92
2-4	61	12.42
1	371	75.56
1470	491	100.00

An analysis of the number of cases of 10 – 24 cases treated by individual consultants over the study period was analysed. This showed that a total of 491 consultants were engaged in the case of adolescents in this age range with cancer (table 8.1). In this ten-year period only 25 consultants (12%) treated more than ten patients. Over 75% dealt with only one patient in ten years with

cancer. With the exception of one neurosurgeon, all the consultants treating more than ten patients were based in the cancer centre. This raises the question of volume related outcomes which have been alluded to in other studies. It also does need to be emphasised that over this period there have been considerable changes in clinical practice, and, for example, in Humberside particularly many of the consultants previously involved with the clinical care of adolescents have retired.

There are no data available at the present time to make comparisons about the current service. Should this study be used as evidence for centralisation of all adolescent cancer care? The arguments that services away from the centre have changed are powerful ones. However, the difficulty in demonstrating that the current services have very different outcomes to that previously demonstrated is that to do so will involve data collection for a further 5 – 10 years before it is possible to demonstrate any differences. Can services be allowed to wait that long to change?

What can be demonstrated is the difference in the qualitative aspects of care. Qualitative work suggests that teenagers gain benefit from being treated with their peers and are prepared to travel for treatment, so it may be that a more centralised model of care has benefits which are qualitative as well as improving survival:

This study challenges the current situation where teenagers are managed in a range of small units. In the absence of evidence to suggest that treatment in

small units is beneficial then the only conclusion that can be drawn is one that supports the development of centralised teenage cancer units.

8.3 The Leeds Adolescent Cancer Unit

The Leeds adolescent unit, operating from a small bay in a ward in St James' Hospital had found that referrals had increased by 116% since the small dedicated facility had been established. This had led to an increase in the drug costs of over £100,000. This is shown in more detail in tables 9.10 -9.11

The proposals for the setting up of an adolescent cancer centre in Leeds are considered in more detail in chapter 9.

9 Economic Issues

9.1 Costs

The financial implications of reconfiguring the management of adolescent cancer services are very significant. A proposal from the Leeds Teaching Hospitals Trust to establish an adolescent cancer unit includes a cost of £1,109,180 [14]. The costs of this development are made up as shown in the following table:

Table 9.1 Breakdown of proposed costs for Leeds Adolescent Unit

Item	Cost (£)
Medical Staff	60,000
Nursing Staff (inpatient)	254,080
Nursing Staff (outpatient)	63,700
Professions Allied to Medicine	42,000
Psychologist	12,900
Administrative costs	18,000
#Other costs (blood, drugs, radiology, pathology)	612,500
Start up costs (1st Year only beds, equipment)	28,000
Domestic and catering costs	60,000
Total costs	**1,109,180**

Source: Leeds Teaching Hospitals Trust

#The other costs are further broken down as follows:

[14] Leeds Teaching Hospitals NHS Trust. The Business Case for Adolescent Cancer Services. November 1999

Table 9.2 Other costs (blood, drugs, radiology, pathology)

Item	Cost (£)
Blood products	144,000
Pharmacy drug expenditure	410,000
Radiology	31,480
Pathology	27,020
Total	612,500

Source: Leeds Teaching Hospitals Trust

9.2 The experience in Leeds

A small teenage cancer trust unit opened in Leeds on 1st June 1998. The original aim was to improve the facilities available in Leeds for teenagers already receiving treatment in the Leeds Cancer Centre. The experience since the opening of this unit has been that there has been a considerable increase in referrals from outside Leeds.

9.3 Health Service Data

Data on all hospital episodes are collected. These data extend to the number of patients, the number of inpatient and day case episodes. These data are collated routinely by hospital information systems. These data are then available to health authorities in order for them to perform their commissioning functions.

Health Service data were collected for adolescents treated between April 1997 - March 1998 from the six health authorities in Yorkshire. This includes all the

data on the patients admitted to the various hospitals but only extends to data on residents from Yorkshire. Thus adolescents treated in the major cancer centres in Yorkshire who are not Yorkshire residents will not be included in the data. Conversely, data on residents of Yorkshire treated outside Yorkshire will be included in the data.

The purpose of examining these data is to assess to what extent there is potential to further centralising the treatment of adolescents and also to attempt to suggest what level of resource might be required to effect such a change in the pattern of clinical activity.

A major weakness in Health Service data is the relative paucity of data on outpatients. Although numbers of outpatient attendances are recorded, there is at the present time no systematic attempt to record either presenting symptoms or presenting diagnosis.

These data do not anonymise hospital of treatment. It is therefore possible to identify where patients received treatment in the major cancer centre i.e. Leeds.

9.4 Results of the Analysis of Health Service Data

Tables 9.3 - 9.5 show the numbers of patients, the number of day case episodes and the number of inpatient treatments between April 1997 and March 1998 in all locations for Yorkshire residents. These data are presented as percentages in tables 9.4 - 9.6.

Table 9.3 Total patients treated in Leeds Cancer Centre and non Leeds locations (April 1997-March 1998)

Age Group	10-14		15-19		20-24	
	Leeds	Non Leeds	Leeds	Non Leeds	Leeds	Non Leeds
Leukaemias (C90-95)	64	40	11	2	14	8
Lymphomas (C81-85)	10	3	18	28	21	86
Hodgkin's (C81)	6	2	8	23	8	61
Non-Hodgkin's (C82-85)	4	1	10	5	13	25
CNS Tumours (C71-72)	33	3	3	4	11	8
Skin Tumours (C43-44)	1	1	1	5	4	7
Bone Tumours (C40-41)	38	6	48	2	1	1
All Tumours (C00-97)	186	61	126	45	73	153

Table 9.4 Day case episodes treated in Leeds Cancer Centre and non Leeds locations (April 1997-March 1998)

Age Group	10-14		15-19		20-24	
	Leeds	Non Leeds	Leeds	Non Leeds	Leeds	Non Leeds
Leukaemias (C90-95)	97	20	15	5	48	5
Lymphomas (C81-85)	9	0	13	44	47	61
Hodgkin's (C81)	4	0	3	44	14	47
Non-Hodgkin's (C82-85)	5	0	10	0	33	15
CNS Tumours (C71-72)	17	0	2	0	4	0
Skin Tumours (C43-44)	0	1	1	4	3	3
Bone Tumours (C40-41)	9	1	22	0	0	0
All Tumours (C00-97)	151	25	58	57	107	84

Table 9.5 In patient episodes treated in Leeds Cancer Centre and non Leeds locations (April 1997-March 1998)

Age Group	10-14		15-19		20-24	
	Leeds	Non Leeds	Leeds	Non Leeds	Leeds	Non Leeds
Leukaemias (C90-95)	68	20	19	2	24	5
Lymphomas (C81-85)	27	3	8	17	21	26
Hodgkin's (C81)	23	2	7	12	12	14
Non-Hodgkin's (C82-85)	4	1	1	5	9	12
CNS Tumours (C71-72)	18	3	2	3	7	8
Skin Tumours (C43-44)	1	0	0	1	1	3
Bone Tumours (C40-41)	42	5	48	3	1	1
All Tumours (C00-97)	220	36	126	34	99	73

Table 9.6 % patients treated in Leeds Cancer Centre and non Leeds locations (April 1997-March 1998)

Age Group	10-14		15-19		20-24	
	Leeds	Non Leeds	Leeds	Non Leeds	Leeds	Non Leeds
Leukaemias (C90-95)	61.5	38.5	84.6	15.4	63.6	36.4
Lymphomas (C81-85)	76.9	23.1	39.1	60.9	19.6	80.4
Hodgkin's (C81)	75.0	25.0	25.8	74.2	11.6	88.4
Non-Hodgkin's (C82-85)	80.0	20.0	66.7	33.3	34.2	65.8
CNS Tumours (C71-72)	91.7	8.3	42.9	57.1	57.9	42.1
Skin Tumours (C43-44)	50.0	50.0	16.7	83.3	36.4	63.6
Bone Tumours (C40-41)	86.4	13.6	96.0	4.0	50.0	50.0
All Tumours (C00-97)	75.3	24.7	73.7	26.3	32.3	67.7

Table 9.7 Day case episodes treated in Leeds Cancer Centre and non Leeds locations (April 1997-March 1998)

Age Group	10-14		15-19		20-24	
	Leeds	Non Leeds	Leeds	Non Leeds	Leeds	Non Leeds
Leukaemias (C90-95)	82.9	17.1	75.0	25.0	90.6	9.4
Lymphomas (C81-85)	100.0	0.0	22.8	77.2	43.5	56.5
Hodgkin's (C81)	100.0	0.0	6.4	93.6	23.0	77.0
Non-Hodgkin's (C82-85)	100.0	0.0	100.0	0.0	68.8	31.3
CNS Tumours (C71-72)	100.0	0.0	100.0	0.0	100.0	0.0
Skin Tumours (C43-44)	0.0	100.0	20.0	80.0	50.0	50.0
Bone Tumours (C40-41)	90.0	10.0	100.0	0.0	0.0	0.0
All Tumours (C00-97)	85.8	14.2	50.4	49.6	56.0	44.0

Table 9.8 In patient episodes treated in Leeds Cancer Centre and non Leeds locations (April 1997-March 1998)

Age Group	10-14		15-19		20-24	
	Leeds	Non Leeds	Leeds	Non Leeds	Leeds	Non Leeds
Leukaemias (C90-95)	77.3	22.7	90.5	9.5	82.8	17.2
Lymphomas (C81-85)	90.0	10.0	32.0	68.0	44.7	55.3
Hodgkin's (C81)	92.0	8.0	36.8	63.2	46.2	53.8
Non-Hodgkin's (C82-85)	80.0	20.0	16.7	83.3	42.9	57.1
CNS Tumours (C71-72)	85.7	14.3	40.0	60.0	46.7	53.3
Skin Tumours (C43-44)	100.0	0.0	0.0	100.0	25.0	75.0
Bone Tumours (C40-41)	89.4	10.6	94.1	5.9	50.0	50.0
All Tumours (C00-97)	85.9	14.1	78.8	21.3	57.6	42.4

Table 9.3 shows that the majority of patients 10-14 years old are treated at some time in Leeds. This extends to 15-19 year olds but the pattern is noticeably reversed for 20-24 year olds.

However, the day case day and inpatient data for 20-24 year olds suggest that most patients do still receive some of their treatment in Leeds. This may well therefore represent a different referral pattern with these patients being seen firstly in local hospitals.

Looking at the data in more detail does suggest a differing pattern of treatment dependent on cancer site. For example, it would seem that a considerable proportion of leukaemias in the younger age groups are being treated locally. However, the management of lymphoma in 15-year olds and upwards is mostly concentrated in local units, a pattern reflected in both inpatient and day case activity. The small numbers of CNS tumours treated outside Leeds are managed in Hull. The data is illustrated graphically in figures 9.1 - 9.3

Figure 9.1

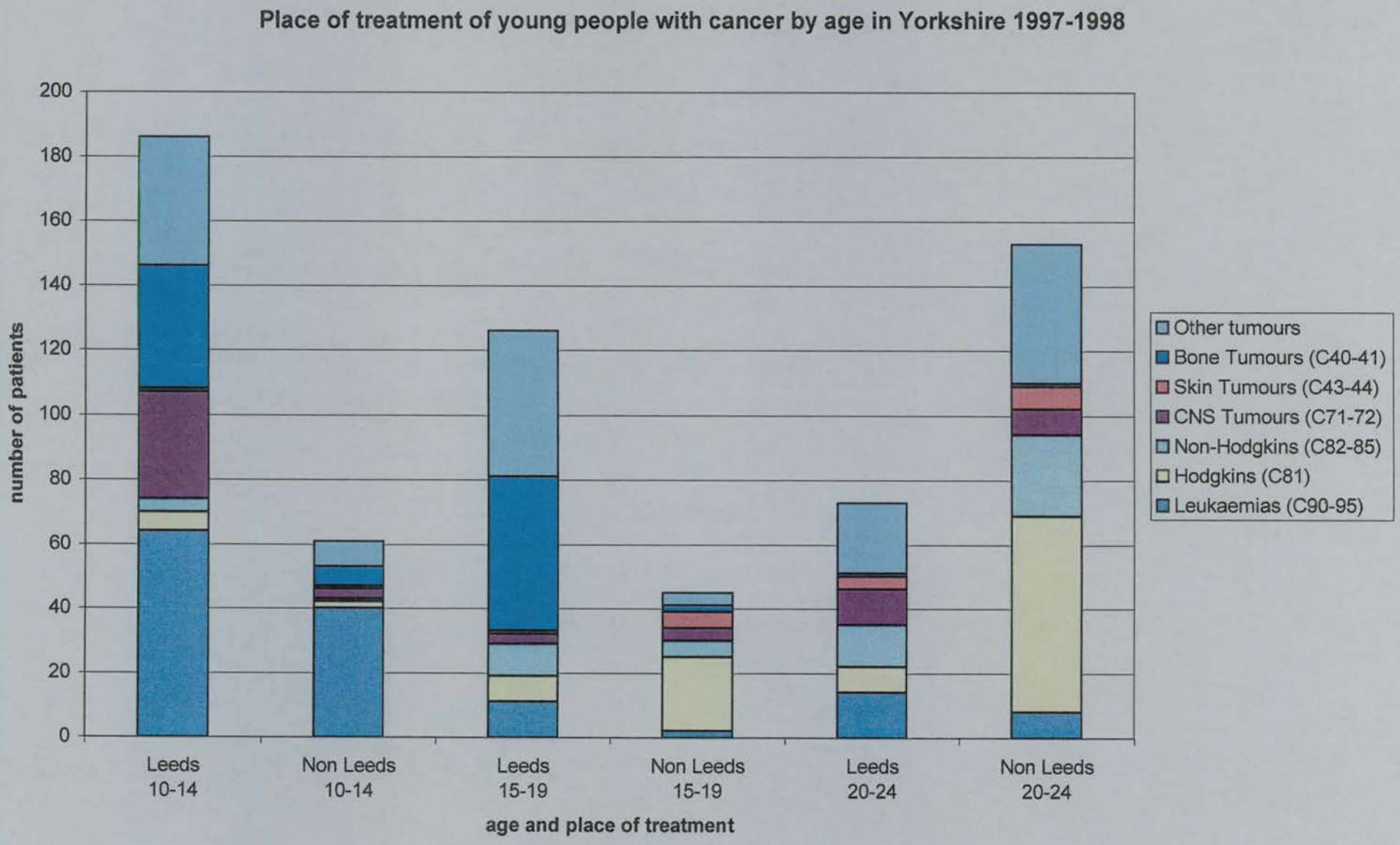

Place of treatment of young people with cancer by age in Yorkshire 1997-1998
number of patients
200
180
160
140
120
100
80
60
40
20
0
Leeds 10-14
Non Leeds 10-14
Leeds 15-19
Non Leeds 15-19
Leeds 20-24
Non Leeds 20-24
age and place of treatment
Other tumours
Bone Tumours (C40-41)
Skin Tumours (C43-44)
CNS Tumours (C71-72)
Non-Hodgkins (C82-85)
Hodgkins (C81)
Leukaemias (C90-95)

Figure 9.2

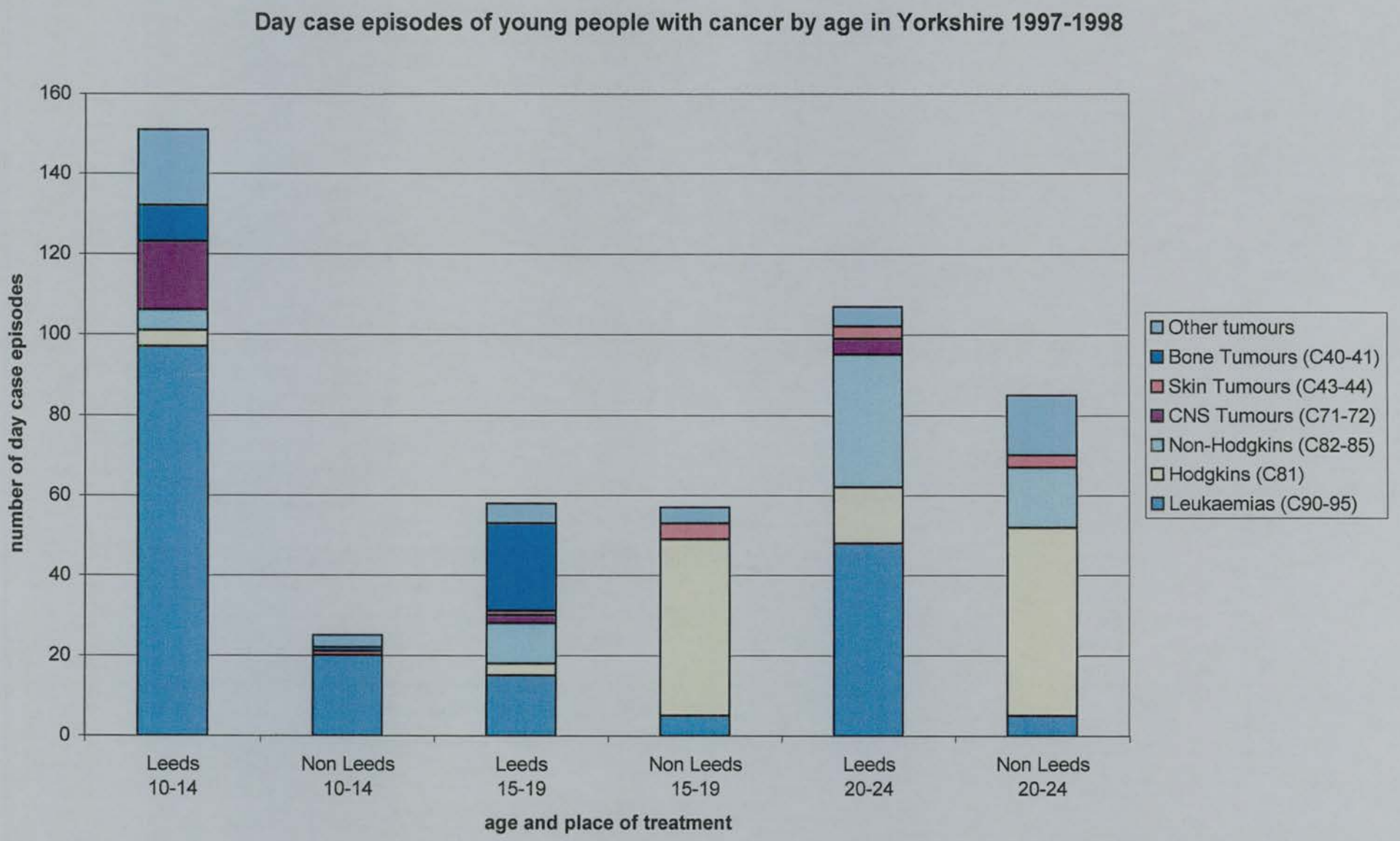
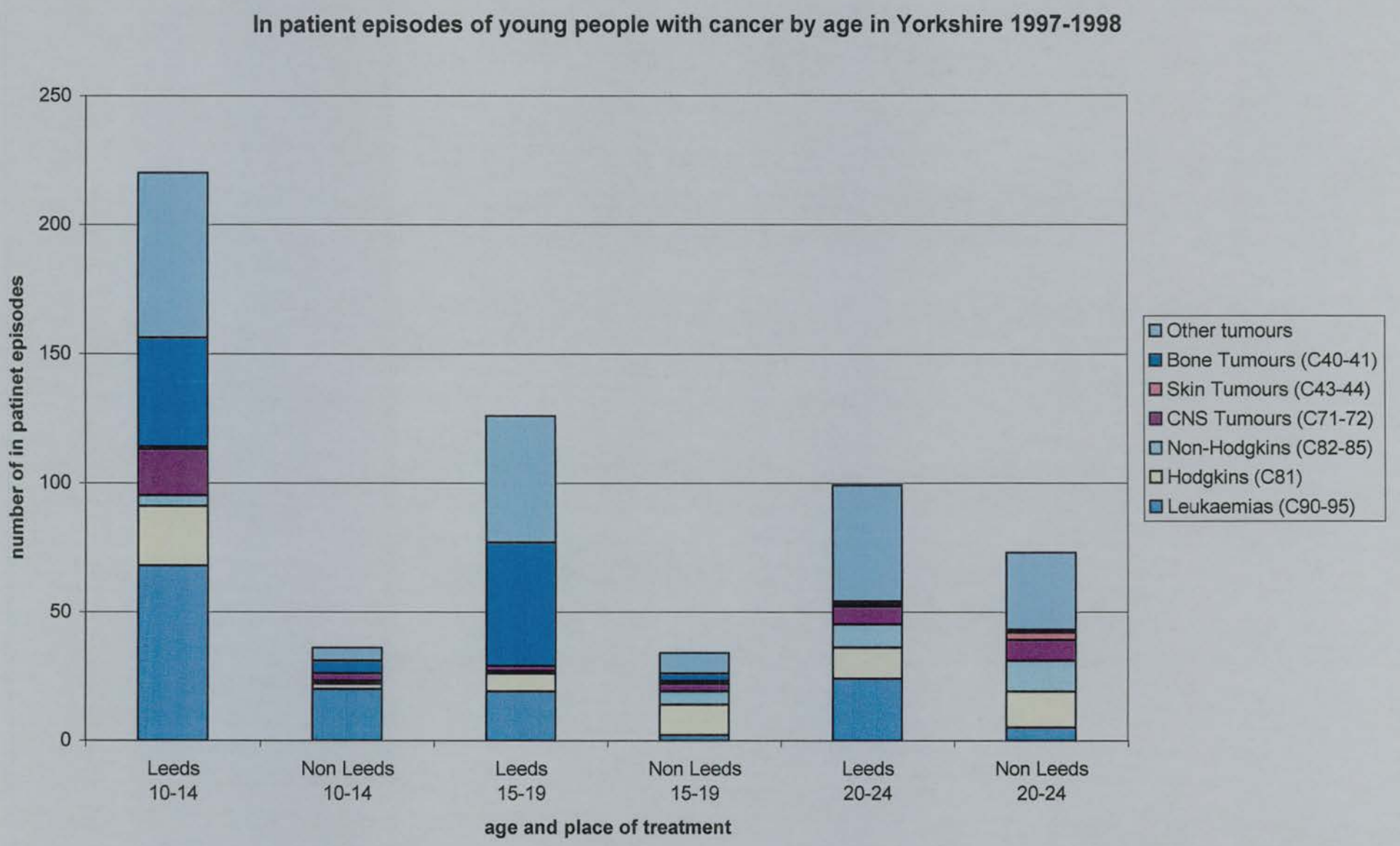

Day case episodes of young people with cancer by age in Yorkshire 1997-1998
number of day case episodes
160
140
120
100
80
60
40
20
0
Leeds 10-14
Non Leeds 10-14
Leeds 15-19
Non Leeds 15-19
Leeds 20-24
Non Leeds 20-24
age and place of treatment
Other tumours
Bone Tumours (C40-41)
Skin Tumours (C43-44)
CNS Tumours (C71-72)
Non-Hodgkins (C82-85)
Hodgkins (C81)
Leukaemias (C90-95)

Figure 9.3


In patient episodes of young people with cancer by age in Yorkshire 1997-1998
number of in patinet episodes
250
200
150
100
50
0
Leeds 10-14
Non Leeds 10-14
Leeds 15-19
Non Leeds 15-19
Leeds 20-24
Non Leeds 20-24
age and place of treatment
Other tumours
Bone Tumours (C40-41)
Skin Tumours (C43-44)
CNS Tumours (C71-72)
Non-Hodgkins (C82-85)
Hodgkins (C81)
Leukaemias (C90-95)

Data were collected in the year prior to establishing this unit and are compared with similar data for the subsequent year. These data are shown in table 9.10

Table 9.10 Change in admissions between 1998 and 1999

	Year One (paediatric oncology ward)	**Year Two (Teenage Cancer Unit)**	**Comment**
Time Period	01/06/97 - 31/05/98	01/06/98 - 31/05/99	Increase
Male	9	26	17 patients
Female	6	15	9 patients
Total	15	41	26 patients
Mean age	14.6 years	16.4 years	1.8 years
Age range	13 - 19 years	13 - 23 years	4 years

Source: Leeds Teaching Hospitals Trust

Table 9.10 shows the considerable increase in the number of admissions between 1997 and 1998. Currently adolescents who are seen in the paediatric oncology departments attend disease specific clinics. These clinics see patients between the ages of 0 and 23. Because of the different needs and time required for these very different age groups, the following table has been derived which shows the likely work load of a clinic which is solely responsible for the needs of young people aged 13 - 23.

Table 9.11

Age range	**Average no of outpatient and day care episodes per week - solid tumours**	**Average no of outpatient and day care episodes per week - haematological malignancies**	**Total number per week**	**Total number per year**
13 - 23 years	22	7	29	1508

Source: Leeds Teaching Hospitals Trust

The business case makes several suggestions as to why this rise has taken place, these are as follows:

- The Calman - Hine Report
- The Development of the Leeds Cancer Centre
- A high profile opening of the unit by a member of the Royal Family
- Education of professionals within the Leeds cancer centre
- Patient preference
- Increased profile of adolescent care within the NHS
- 'Word of mouth'

The business case contains data that does support the view that an increased number of patients are being managed in the Teenage Unit who would have previously been managed elsewhere. This applies particularly to the management of leukaemia and brain tumours where the biggest increases have been seen.

Health Authorities in Yorkshire are now being asked to invest in this service. Broadly speaking, investment in this situation may come from a number of sources. These are:

1. from within the Trust itself
2. From additional investment by health authorities
3. From charitable donations
4. From a transfer of costs from other places of treatment no longer providing those services.

Each of these is now considered in some more detail.

1. From within the Trust. A scale of development of the order of £1 Million is unlikely to be made through internal cost savings through transfer of activity or efficiency.
2. From additional investment from health authorities. This is the most likely potential sources of funding. Each year, health authorities consider priorities for additional investment. A case such as this with evidence of benefit is likely to find much more likely to find favour with health authorities than other cases with scanty background information or evidence of effectiveness. However, health authorities have an ever-increasing number of priorities to invest in and the need for improving services for adolescents with cancer will need to be set against other priorities.
3. Charitable donations. Charitable donations within the NHS can be a valuable source of funding. However, such funding is usually only made available for capital developments rather than for the ongoing costs of the facility. Charitable sources may well be a useful source of funding some of the start up costs for the unit.
4. Transfer of costs from other units. The transfer of costs from units already providing treatment is always considered when new services are developed. However, this is only possible when it is possible to release 'stepped costs' from a contracting unit. In the case of adolescent cancer, it is unlikely that the shift of such a small number of patients from any one location will release any costs as most, if not all of the pre-existing infrastructure (staff, wards, beds etc.) will need to be retained.

9.5 Service Issues Conclusions

If health authorities accept the evidence for the development of an adolescent cancer unit, then it is unlikely that there will be any transference of costs from other locations or that there will be a significant level of funding from other sources. However, there will be scope for a more detailed examination of the costs should the proposal to establish an adolescent cancer unit be agreed. This service will only be established with a real investment in costs.

10 Discussion and Recommendations

10.1 General

This study confirms the preliminary examination of previously published data which suggested that cancer in young people is no more prevalent in the Northern and Yorkshire Region than other parts of the world, although comparisons cannot be exact because of the paucity of published studies and the different age groups involved in the other published analyses. The study also confirms that there are few differences in the incidence of cancer in adolescence in the counties of the region. Some small differences do exist e.g. epithelial cancers in Humberside and these differences merit further investigation – but these could have occurred by chance simply because of the number of analyses which were undertaken (even at the normal level of accepted statistical significance, a chance observation can occur , by definition one in twenty times).

The analysis of the routine data has shown the wide variety of cancer which affects young people and that traditional methods of analysing the data using ICD 9 and 10 may not be the most appropriate way of understanding malignancy in this age group.

The principal contribution to the debate comes from the survival analyses and from the qualitative study.

10.2 Discussion of Hazard Ratio methods survival results

These types of analyses are important from both a clinical and public health perspective. Population based survival rates are published less frequently than results of clinical trials.

The purpose of this study was to investigate the alleged effects of the place of treatment on outcome and other variables.

10.2.1 Place of residence

Significant differences were observed in the place of residence of patients with cancer. The significantly worse survival in Humberside and North Yorkshire is not easily explained. The effect is seen in leukaemias and is difficult to explain, although the differences are large. This suggests that further investigation is warranted. Data shown in Tables 9.3 - 9.8 suggest that already most of this treatment is centralised with the exception of treatment for the 20-24 year old group.

The reasons for the apparent difference in survival are unclear. Similar effect is seen in North Yorkshire with non-Hodgkin's lymphoma. Again this remains unexplained. Overall, in individual cancers there was a suggestion that overall survival is better in West Yorkshire where the teaching hospital is located. The differences between the geographical areas of Yorkshire are notable. Attempts were made to examine hospital of treatment in the cancer registry datasets, but

use of hospital of treatment filed in the dataset was unreliable, and on discussion with some of the clinicians concerned it was apparent that assigning a single hospital to a patient was inappropriate, as many of the patients had been treated in a number of units. Thus it was not possible to be certain where the patient received the significant part of their treatment. Given that previous studies have indicated that cancer is both more prevalent and has a poorer outcome in those areas with lower socio-economic status (146) the findings presented here are counter intuitive in that West Yorkshire and Humberside are less socio-economically affluent than North Yorkshire.

The findings of these analyses show that there is a statistically significant difference in outcome between the three geographical areas. Geographical differences in survival in Yorkshire could be due to one of 3 explanations.

Could these differences have occurred by chance? This cannot be totally excluded, although the size of the differences observed would suggest otherwise. Alternatively, the statistical modelling failed to take account hospital treatment differences across the region. The observed difference in survival may then have disappeared in the multivariate analysis.

Within these data, dose response relationships might have been expected within the individual diagnostic categories. However, the small numbers involved in each of these groupings, even over a ten-year period, make it difficult to draw such conclusions. Even extending the study period is unlikely to be helpful, as the extended study period is likely to encompass considerable

variation in treatment and management. Other publications in Yorkshire have previously demonstrated a poorer outcome from treatment in other cancer areas. This was most recently reported in a poorer outcome for brain tumours (in Humberside)– which of course is an important group amongst adolescents.(147)

The second possibility is that the epidemiology of cancer differs significantly across the North of England and that a systematic pattern of presentation may have occurred whereby more or less advanced cases appear in one place or another. There was no evidence to suggest that this might be a possibility, but clinicians in the area have suggested that more aggressive malignancies are more common in Humberside than elsewhere (R.Patmore – personal communication).

Further work needs to be done to explore potential differences in case-mix particularly in staging data which was, but this is likely to require a new study rather than utilising existing data collection systems.

The third possibility is that the differences in outcome are related to treatment and or the organisation of clinical care. All the consultants treating more than thirty patients (an average of three per year) were based in a cancer centre. This raises the question of volume related outcomes which have been alluded to in other studies. It also does need to be emphasised that over this period there have been considerable changes in clinical practice, and, for example, in

Humberside particularly, many of the consultants previously involved with the clinical care of adolescents have retired.

There are no data available at the present time to make comparisons about the current service. Should this study be used as evidence for centralisation of all adolescent cancer care? The arguments that services away from the centre have changed are powerful ones. However, the difficulty in demonstrating that the current services have very different outcomes to that previously demonstrated is that to do so will involve data collection for a further 5 – 10 years before it is possible to demonstrate any differences.

Although it is difficult to resolve the exact reason for these findings, it should be emphasised that the case data is retrospective in nature, comprising malignancies diagnosed between 1985- 1994

Population density analysis on the Yorkshire data (not possible for the Northern data) suggests that those living in more dense areas are more likely to have a poorer outcome, after accounting for socio-economic status. This may be explained by ethnicity, because non-whites tend to live in areas of very high population density (correlation coefficient =0.41 for 16-29 year olds), such as Bradford and Leeds, and a previous UK study has suggested Asians have poorer prognosis than native white children. A lack of Asian numbers in the data prevented further analysis (148).

A further study is needed to determine the reasons for these differences. The data on hospital of treatment in its current form are less than clear and needs further study. However it is unlikely that this question can be answered with the

current data set and that a more sophisticated piece of research will be required.

10.2.2 Period of Diagnosis

Significant improvement in survival has been demonstrated in the second period of the study with an improvement of 27%, most markedly seen in non-Hodgkin's Disease. This is clearly encouraging and replicates what has been reported in other studies.

10.2.3 Size of treating hospital

The results of the place of treatment are equivocal, if anything showing some survival advantage in being treated away from the centre. However, the difficulties in classifying the treating hospital, together with the potential inaccuracies in the initial source data mean that no firm conclusion is possible in relation to place of treatment in this study.

10.2.4 Social Class

No difference could be demonstrated in the county results due to social class differences. However, it does need to be emphasised that the method used in this study (as in many others) used a proxy measure based on address to allocate social class. Clearly this is crude and the approach has been criticised by some authors (149), (150)

The results of the hazard ratio approach are consistent with the results using Kaplein Meier techniques, and therefore demonstrate consistency.

10.3 Discussion of referral data analysis

One of the issues that the study highlights is whether older patients with lymphoma and leukaemia should be treated centrally. There is a suggestion from the analysis of outcomes that the outcome is worse in the older age groups. This may therefore suggest that patients treated in the cancer centre may have a better outcome, but there is a weakness in the lack of availability of case mix data. However, it seems improbable that patients with lymphomas and leukaemia have an inherently poorer prognosis by living outside Leeds. There is a suggestion therefore that further centralisation of the management of these two groups of conditions may lead to improved outcomes. However, the noticeably worse outcome of 10-14 year olds with Hodgkin's disease living in North Yorkshire and Humberside does not neatly fit this conclusion.

The relatively small numbers of patients each year with cancer in this age group and therefore in each unit in the region would suggest that it would be difficult to release resources in the periphery for investment in the development of an adolescent cancer centre

10.4 Discussion of the qualitative research

The literature review already has identified features of how improvements might be made to the management of adolescents with cancer. The qualitative research revealed significant common themes. It was not surprising that the first priority of those patients who were involved was concentrated on survival. The support available within the adolescent unit was clearly felt to be important

and very different to that experienced in other units, either in other hospitals or in either paediatric or adults wards in other parts of the main cancer centre.

The importance that was placed on being among others with similar problems was notable and is not unexpected given the way that young adults tend to share problems and life experiences in groups.

The high priority placed on education reflects a desire to be seen as normal. This was not appreciated in any sense by the healthy control group, who clearly thought that any excuse to get away from lessons was paramount.

Outpatient management of patients could be improved by providing a separate area for adolescents. Some of the experiences reported by the adolescents were wholly unacceptable and urgent attention now needs to be given to clarify referral pathways to ensure that speedy diagnoses are made and that appropriate referral is made as quickly as possible

10.5 Final Conclusions

The results of both the qualitative research and quantitative work suggest that the development of an adolescent cancer centre may be beneficial both in terms of improving survival and by being able to offer a better standard of care to do more than aid survival –although the results are far from conclusive.

The limitations of the evidence are as follows:

The spatial analysis is crude. However, the ideal analysis based on postcode data was not possible for confidentiality reasons. Having postcode data would have allowed more complex analysis using a geographical information system which would have allowed much more sensitive geographical analysis. It also needs to be remembered that multiple analyses can produce unexpected chance findings. The findings described in this study may fall into this category, but as previously discussed, there is some consistency with other previous findings.

Qualitative research does not aim to provide conclusive answers to research questions. Qualitative research inevitably involves a relatively small number of subjects and findings of qualitative research cannot be extrapolated to wider populations in the same way as can be done with quantitative research.

The development of a small unit in Leeds, effectively by rearranging the previous facilities, has provided the opportunity for some of the qualitative

issues to be tested. It has to be accepted that a randomised control trial in this situation is impossible and that it is unlikely to be able to gain much better evidence for the improved management of adolescents with cancer, than has been demonstrated in this study.

10.6 Recommendations for further work

There is need for further work, this should be centred around two areas in the first instance:

1. Work to identify the factors associated with the demonstrable differences in survival. Has this effect continued?
2. The development of a quality of life tool for adolescents looking at immediate quality of care and of quality of life in the periods following treatment.

Box 10.1 Summary of Conclusions from Epidemiological Study

- Improvement in survival over ten year period
- Females survival greater than males
- Some unexplained variation in incidence rates
- Survival not demonstrably improved in large cancer centres
- Unexplained greater mortality in Humberside
- Poorer survival in residents of Humberside
- Survival gets worse with age at diagnosis
- No demonstrable differences in epidemiology in former Northern and Yorkshire Regions

Box 10.2 Summary of Conclusions from Qualitative Studies

- Most important feature of cancer care is deemed to be survival
- Aspects of care are very important - particularly environment
- Adolescents are probably best managed in a special unit
- Education is an important consideration to many individuals
- Shared care is the preferred model of care among consultants in the peripheral hospitals, with some care being undertaken both in the centre and the unit.
- Outpatient facilities need to be considered when improvements in care of adolescents are being considered

The hypotheses to be tested were set out in paragraph 2.5.2. These were:

1. That place of treatment results in improved survival

2. That the incidence of cancer in 10-24 year olds does not differ across the Northern and Yorkshire Region

3. That the quality of care which can be offered by specialist teenage units is no better than that offered by smaller, local hospitals.

Hypothesis 1. Place of treatment. The conclusion concerning treatment is equivocal, but is suggestive that there may be some relationship between an improved outcome and being treated in a larger centre. However, the quality of the data regarding place of treatment meant that a firm conclusion could not be made. This study has strongly suggested that survival differs by geographical location and that this is not explained by differences in incidence, casemix, deprivation or by population density. The possibility that these differences occurred by chance cannot be excluded.

Hypothesis 2 There is no difference between the incidence of cancer in 10 - 24 year olds in Yorkshire, with the exception of carcinomas which showed a slightly higher incidence in East Yorkshire, again the possibility that this was simply a chance finding as a result of the large numbers of statistical analyses which were undertaken.

Hypothesis 3 There may be distinct benefit of large centres and specialised adolescent cancer units being able to provide a better quality of care and more closely meet the needs of the patients who are treated in such a unit. The

evidence supporting this comes from both the quantitative work and the qualitative studies. The qualitative work, though limited is powerful.

10.7 Concluding note

Evidence for policy change in a complex area such as this is difficult to assemble. Ideally more studies need to be carried out, but the difficulty with this approach is that answers from further studies, especially where such small numbers are concerned, will take a long time to materialise. Some of the evidence in this study (especially the qualitative study suggests that policy decisions cannot wait). It also needs to be remembered that the evidence presented here is far stronger than that used in decisions about service development currently employed.

This work has been published in the European Journal of Cancer (151) (attached in the appendix). In addition, health authorities in Yorkshire have agreed to proceed with the proposed adolescent cancer unit in Leeds as described. The unit will be fully funded from April 2002.

It has been decided to examine many of the unanswered questions in this thesis by a prospective audit of the experiences and outcome for a cohort of adolescents with cancer. In the first instance this will be confined to the Northern and Yorkshire Region. There is a strong possibility, following a successful pilot that this study will be undertaken at a national (England) level. Preliminary discussions have taken place with the National Cancer Director to this effect. It is also envisaged that National Cancer Guidance will be published

on the management of cancer in adolescents (personal communication Professor Mike Richards – National Cancer Director [England]).

Annex 1 - The Carstairs and Morris index of deprivation

The Carstairs and Morris index was originally developed in the 1980s using 1981 census data. It is composed of four indicators which were judged to be representative of material deprivation. (130) It is said to correlate well with a range of health measures (152).The four indicators are combined to form a composite score. The composite score is divided into seven separate categories, ranging from very high to very low deprivation. The seven categories were designed to retain the discriminatory features of the distribution of the deprivation score, rather than to ensure equality of numbers between each deprivation category. Some very small postcode sectors were excluded and do not have a score. The index was designed with the expectation that it would be mirrored by direct measurement of household income if that were possible. The four variables are as follows:

- Overcrowding: persons in private households living at a density of more than one person per room as a proportion of all persons in private households
- Male unemployment : Proportion of economically active males who are seeking work
- Social class 4 or 5 : Proportion of all persons in private households with head of household in social class 4 or 5
- No car : proportion of all persons in private households with no car

All the proportions are calculated on the households in a given postcode sector.

Problems in the use of area classifications

There are some possible problems in the use of the Carstairs index (which may apply to other similar area classifications). (153)

- Firstly, the index is based on assumptions about the variables that best represent material deprivation. For instance the possession of a car may be an essential in some (e.g. rural) areas and not represent the access to material resources that it appears. Indeed it may be a drain on resources that people cannot avoid. (153)
- Secondly, areas are not internally homogeneous; populations containing a mixture of deprived and less deprived households are likely to have middle ranking scores (153). Such mixed populations would be more likely to occur in rural areas. Therefore area based scores are likely to provide a better indication of deprivation in urban than rural areas.

  There are fewer areas of deprivation in categories 1,2,6 and 7 in the smaller areas and more rural areas. This can be explained in several ways:

  - There may be less deprivation in such areas
  - The population may be mixed leading to more postcode sector areas with middle ranking scores, despite there being similar numbers of deprived individuals across the whole area
  - Car ownership, being more essential than in more urban areas, may be pushing more people into poverty
  - A combination of the above
- Thirdly the scores from postcode sectors with small populations (less than 2000) are based on census counts which are particularly susceptible to random variation (153)

Fourthly the ecological fallacy is an important potential limitation of area based measures. It results from the false assumption that inferences can be made about individual phenomena based on observations of groups. (154) The Carstairs deprivation category may be associated with an individual's risk of adverse health outcome through an individual's personal experience of deprivation, and/or the effect of living in a deprived area. It has been estimated that the deprivation effect on mortality is entirely explained by the presence of deprived individuals within those areas (155). It remains possible however that area level effects, in addition to those expected from the concentration of individuals, may exist for certain health problems. (155)

The process of categorising areas (postcode sectors) by proportion of individuals can lead to difficulties in interpretation. For instance, Sloggett and Joshi have estimated that 55% of the most deprived individuals in England and Wales live outside the 20% of areas that are most deprived (155).

- Finally, area based scores such as the Carstairs index use census variables for their creation and can therefore, only be updated every 10 years. A change in the Carstairs score from 1981 to 1991 census may represent a true change in the deprivation level in an area, or it may reflect a change in the relative proportions of the component variables. (153)

In an ideal situation, therefore, the use of reliable individual measure of deprivation, which could be regularly updated would allow each of these effects to be accounted for at both the individual and the area levels and more reliably monitored over time. However, at present there is no readily available, validated measure that would be acceptable for general use.

Annex 2 - The SEER Database

Background

The Surveillance, Epidemiology, and End Results (SEER) Program of the National Cancer Institute is the most authoritative source of information on cancer incidence and survival in the United States. Case ascertainment for SEER began on January 1, 1973, in the states of Connecticut, Iowa, New Mexico, Utah, and Hawaii and the metropolitan areas of Detroit and San Francisco-Oakland. In 1974-1975, the metropolitan area of Atlanta and the 13-county Seattle-Puget Sound area were added. In 1978, 10 predominantly black rural counties in Georgia were added, followed in 1980 by the addition of American Indians residing in Arizona. Three additional geographic areas participated in the SEER program prior to 1990: New Orleans, Louisiana (1974-1977); four counties in New Jersey (1979-1989); and Puerto Rico (1973-1989). The National Cancer Institute also began funding a cancer registry that, with technical assistance from SEER, collects information on cancer cases among Alaska Native populations residing in Alaska. In 1992, the SEER Program was expanded to increase coverage of minority populations, especially Hispanics, by adding Los Angeles County and four counties in the San Jose-Monterey area south of San Francisco.

Geographic areas were selected for inclusion in the SEER Program based on their ability to operate and maintain a high quality population-based cancer reporting system and for their epidemiologically significant population subgroups. The population covered by SEER is comparable to the general U.S. population with regard to measures of poverty and education. The SEER population tends to be somewhat more urban and has a higher proportion of foreign-born persons than the general U.S. population.

SEER Database

The SEER Program currently collects and publishes cancer incidence and survival data from 11 population-based cancer registries and three supplemental registries covering approximately 14 percent of the U.S. population. Information on more than 2.5 million in situ and invasive cancer cases is included in the SEER database, and approximately 160,000 new cases are accessioned each year within the SEER catchment areas. The SEER registries routinely collect data on patient demographics, primary tumour site, morphology, stage at diagnosis, first course of treatment, and follow-up for vital status. The SEER Program is the only comprehensive source of population-based information in the United States that includes stage of cancer at the time of diagnosis and survival rates within each stage. The mortality data reported by SEER are provided by the National Centre for Health Statistics.

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Appendix

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Appendix

Survival in adolescents and young people with cancer aged 10-24 years in the former Northern Region 1985-1994

Data included in this analysis were obtained from the Northern Children's and Young Peoples Tumour Registry and relates to data between 1985 and 1994 (with follow up up to 1996). The methods of data collection and its limitations are considered in section 5.2 of the main thesis and in a recent publication from the registry (1).

In this appendix 5 year survival rates have been shown calculated using the Kaplein Meier method (2).

Overall survival (figure A.1)

Of the 1036 subjects in the case series, 305 had died by the end of the follow up period. Overall survival at five years was 74%, this was broadly comparable with the Yorkshire 5 year survival rate for the series of 72%.

Year of diagnosis (figure A.2)

As in the Yorkshire data, comparison was made between two time periods, 1985-1989 and 1990-1994. It can be seen in this figure that unlike in Yorkshire survival does not appear to have improved over these two time periods.

Age group (figure A.3)

Comparisons have been made between age groups at the time of diagnosis. Significant differences were noted (p=0.03). However, unlike in Yorkshire the poorest outcome was experienced in the 15-19 year group. Patients aged 20-24, again had the best outcome. This is likely to be due to case mix (a predominance of Hodgkins lymphoma for which there is a relatively good prognosis).

County of Residence (figure A.4)

Differences were observed, but unlike the Yorkshire data these differences did not reach statistical significance (p=0.114)

Sex (figure A.5)

As is widely reported elsewhere, better outcomes were seen in females compared to males. This difference was statistically significant (p= 0.0236)

Hospital Type (figure A.6)

Treating hospitals were divided into 'centre' and district hospitals. Centres were the pre-existing cancer centres which have been designated in the Northern Region (Middlesbrough and Newcastle). Significant difference were noted between centres and district hospitals, with a worse prognosis in the 'centre' hospitals.

Survival By Cancer site

Figures A.7-A.13 show the survival curves for the main cancers in the 10-24 year age group. These show similar patterns to those for Yorkshire.

Cox Regression analysis

The Cox regression analysis shows very few significant results. There is a suggestion that residents in county Durham may fare worst and this is particluartly seen in carcinomas. However confidence limits are wide, and this difference needs ot be interpreted with caution. Follow up over a longer period is recommended.

Discussion

Survival in this age group did not appear to differ significantly compared with other studies and the data presented in this thesis for those patients resident in Yorkshire. Significant differences in survival have not been demonstrated between counties of residence unlike in Yorkshire. However, it is interesting to note that, although not reaching statistical significance, the best outcome is in the residents of Tyne and Wear, the closest county to the cancer centre and similar to the pattern observed in Yorkshire.

The differences that were demonstrated between hospital of treatment were to be expected as it was not possible in these data to take account of case mix. It seems plausible that more seriously ill adolescents are more likely to be managed in the cancer centre.

Conclusions

Survival analysis for the former northern region patents in this study appears to be similar to that observed in Yorkshire, although the inter-county variations have not been identified to the same extent in the Northern region, though this may be suggested in the data. More research is clearly required in this area, emphasis should be given to investigating this issue over a longer time period.

Figure A.1 All cancer survival curve

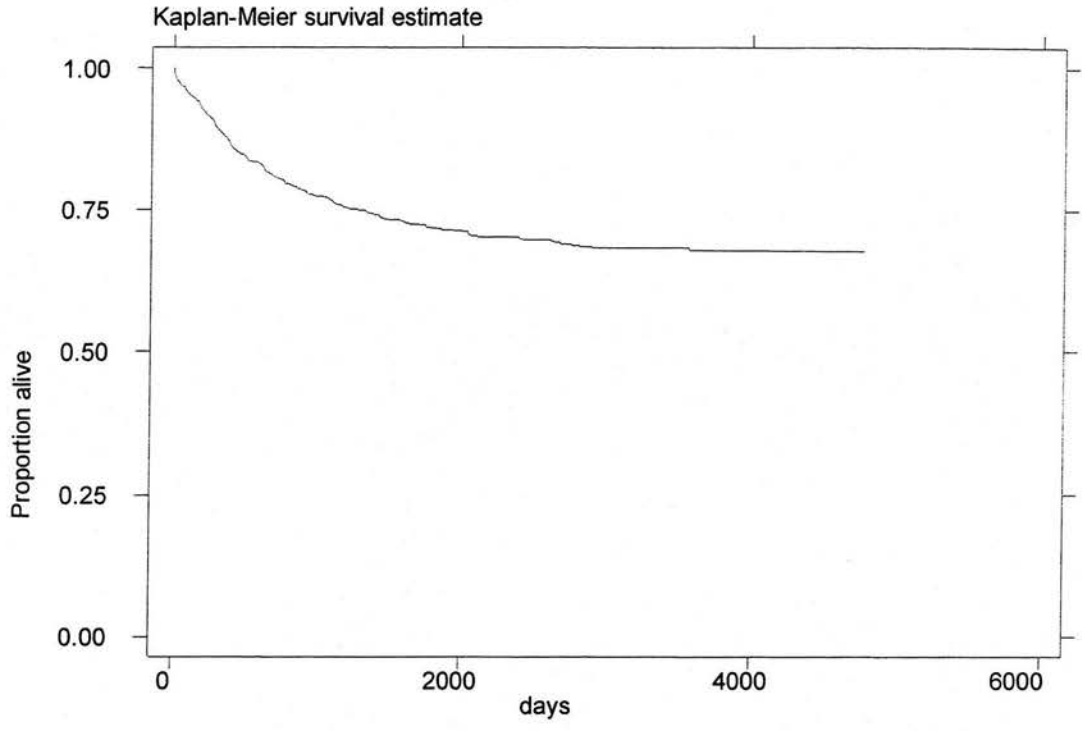
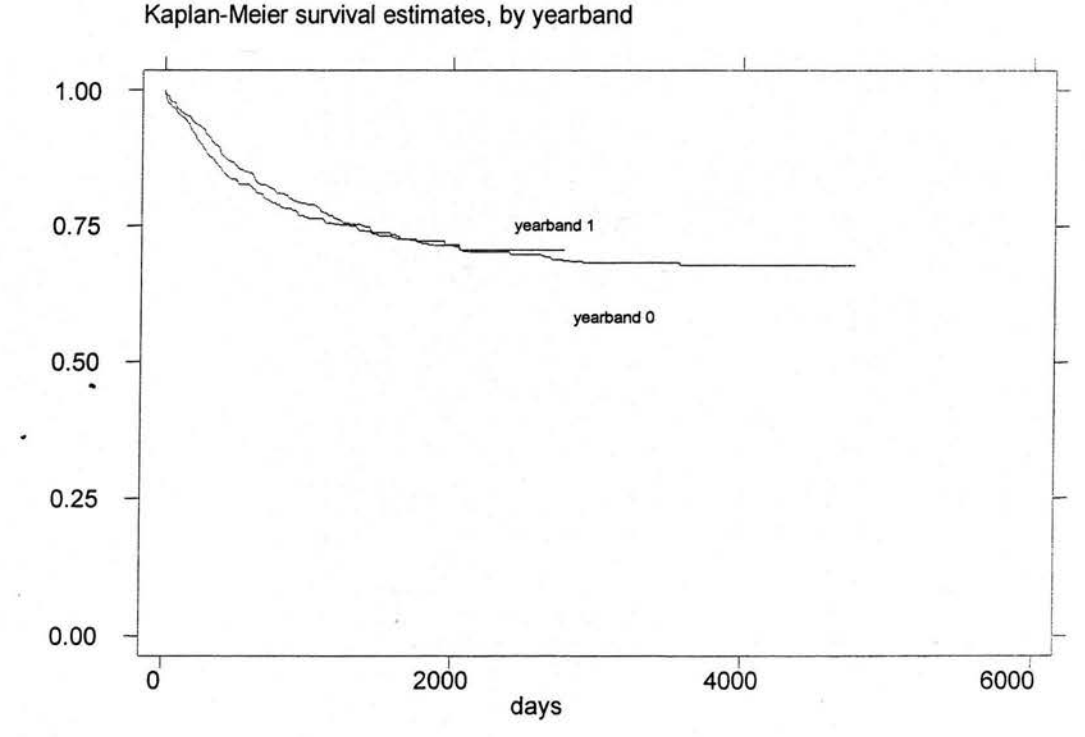
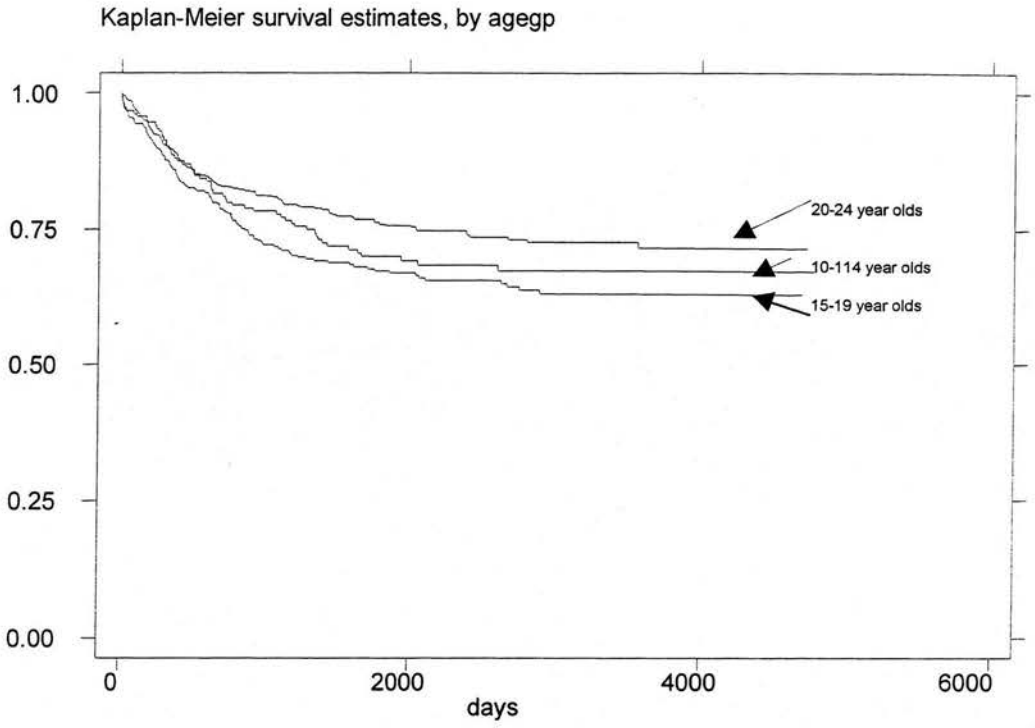


Figure A.2 Survival by year of diagnosis



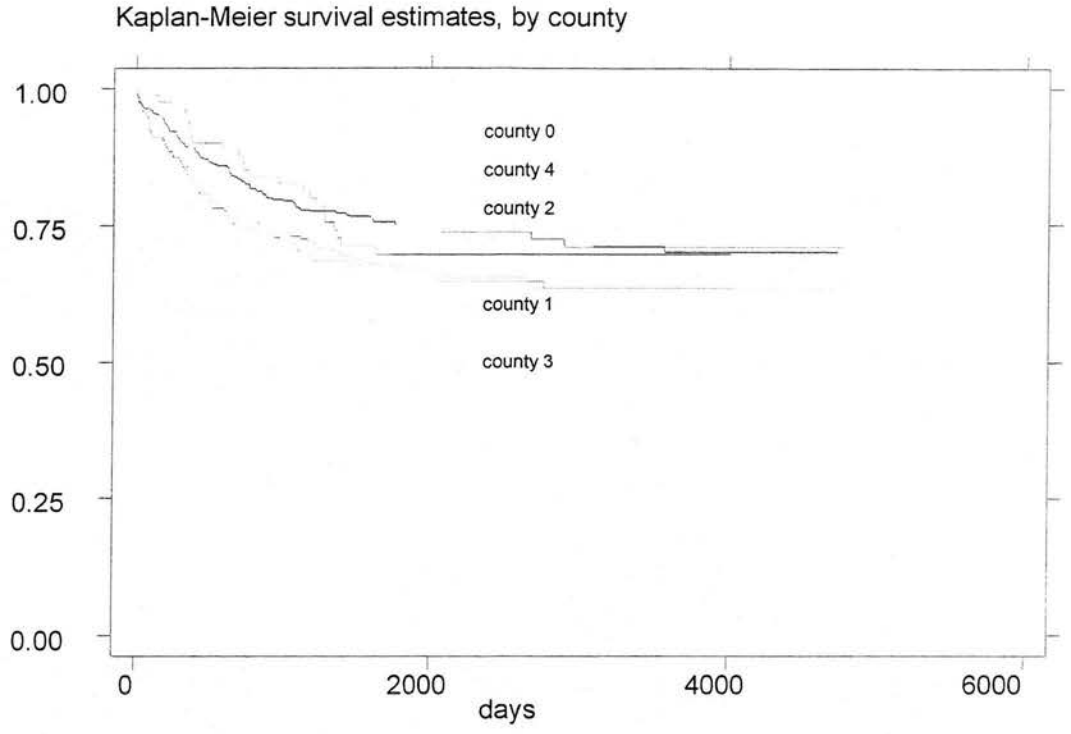
year band 0 = 1985 - 1989
year band 1 = 1990 - 1994
p= 0.8352

Figure A.3 Survival by age group



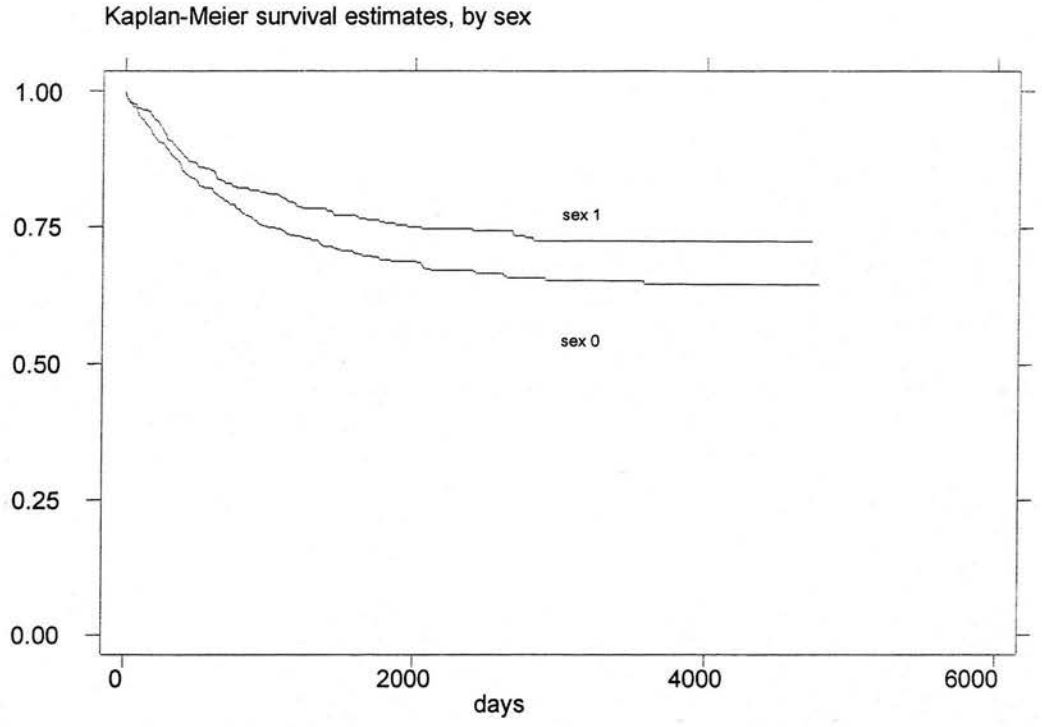
p=0.03

Figure A.4 Survival by County of Residence



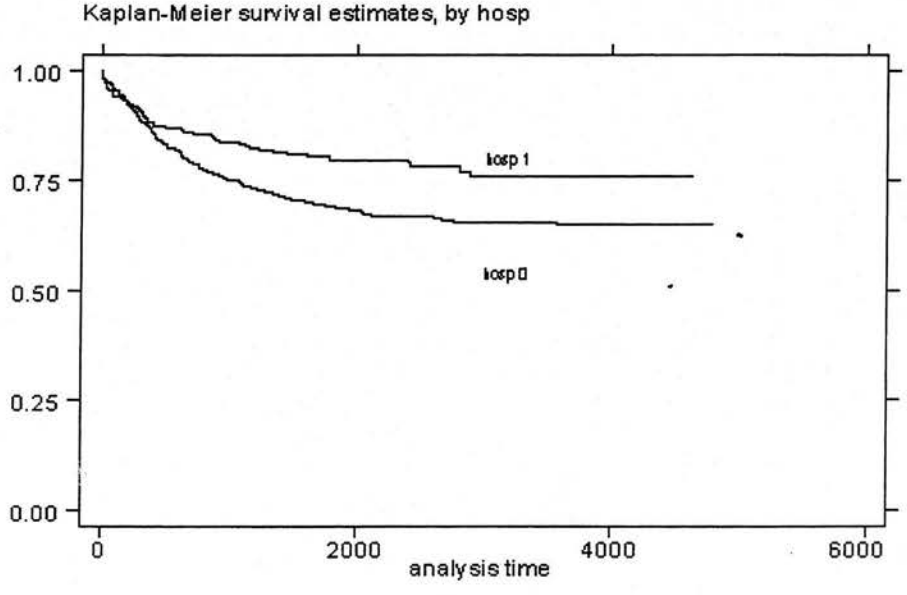
county 0 = Tyne and Wear
county 1 = Teesside
county 2 = Cumbria
county 3 = County Durham
county 4 = Northumberland

Figure A5 Survival by Sex



sex 0 = males
sex 1 = females
p= 0.0236

Figure A.6 Survival by hospital type



hosp 1 = district hospital
hosp 0 = centre hospital
p= 0.0024

Figure A.7 Leukaemias

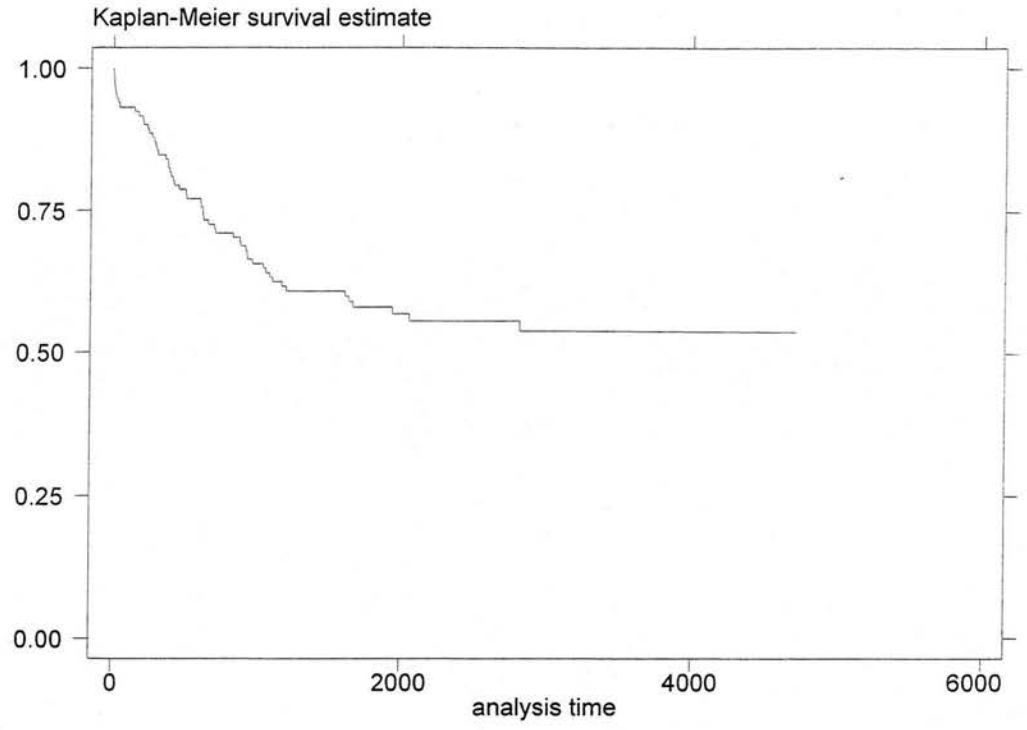


Figure A.7.1 Acute lymphoblastic Leukaemia

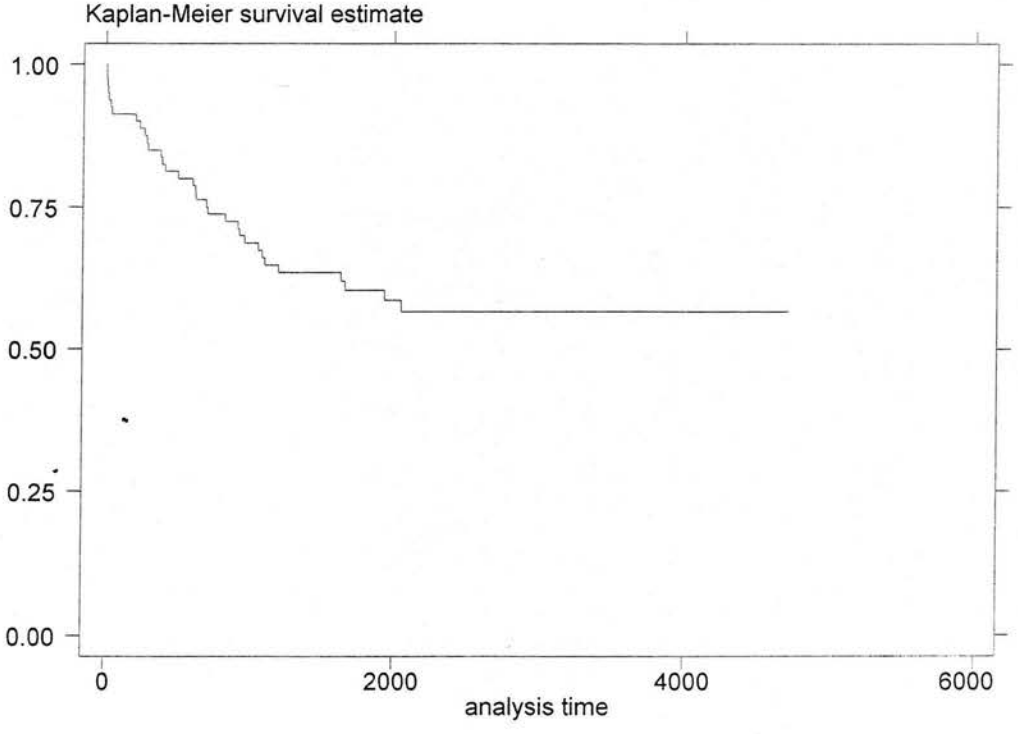


Figure A.7.2 Acute Myeloid Leukaemia

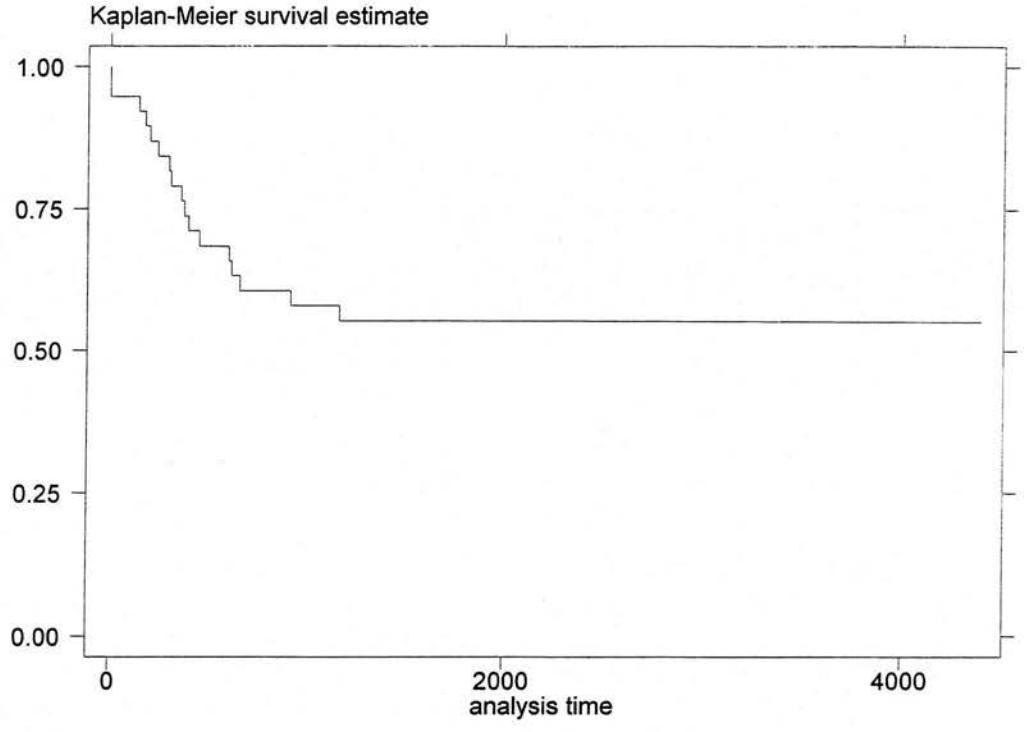


Figure A.8 Lymphomas

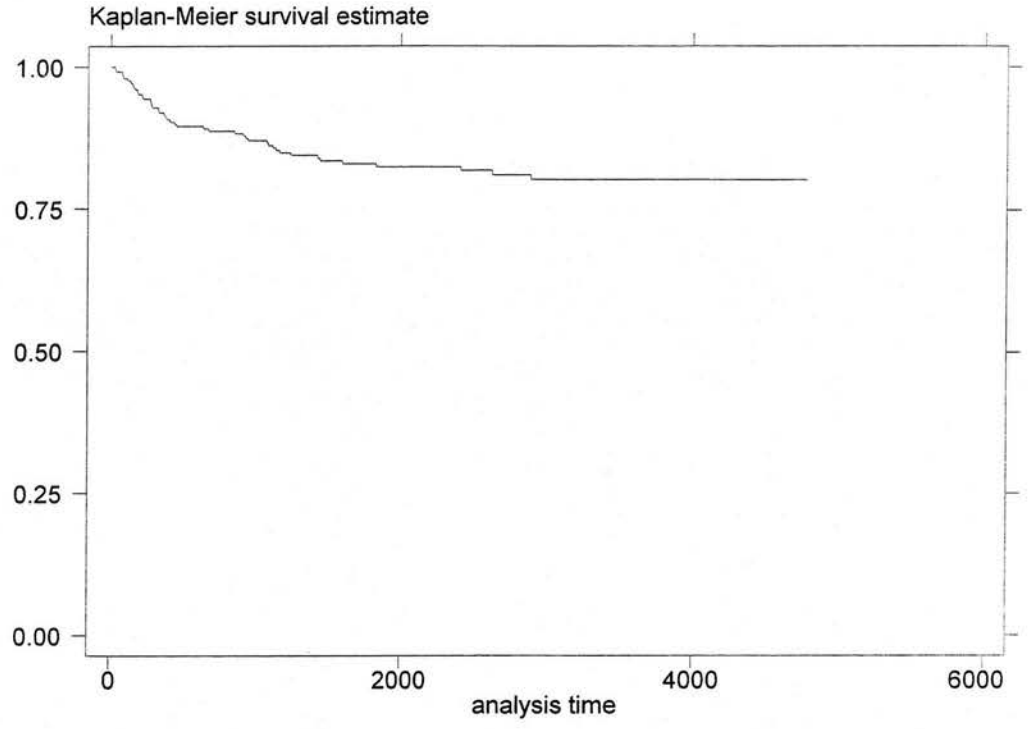


Figure A.8.1 Hodgkin's Lymphoma

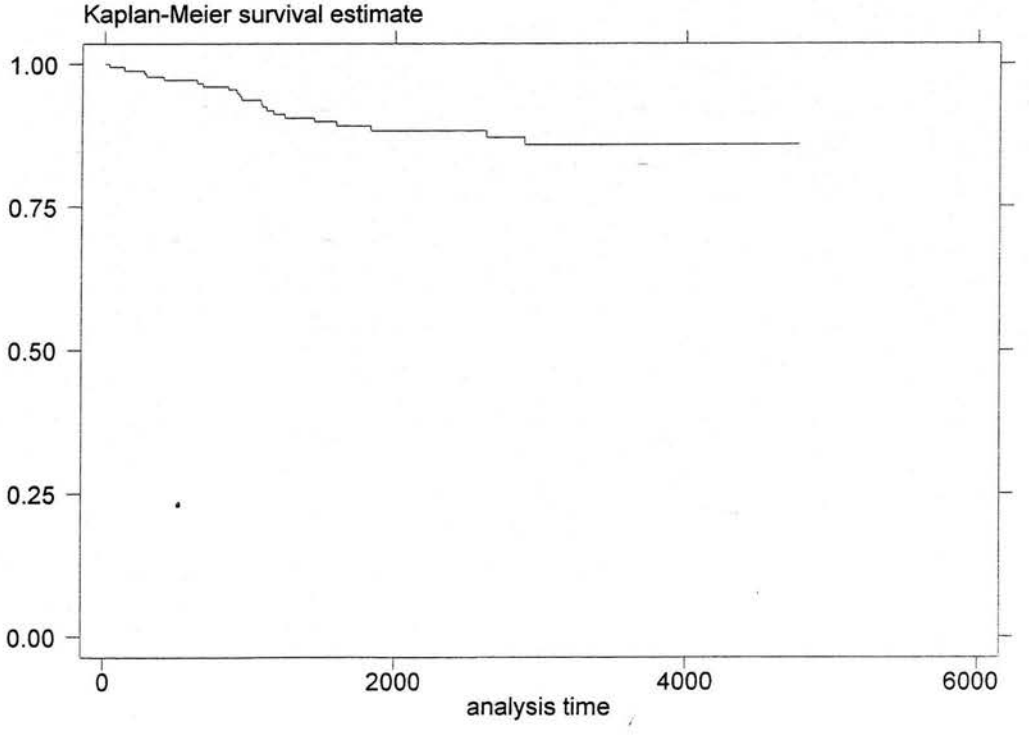


Figure A.8.2 Non- Hodgkin's Lymphoma

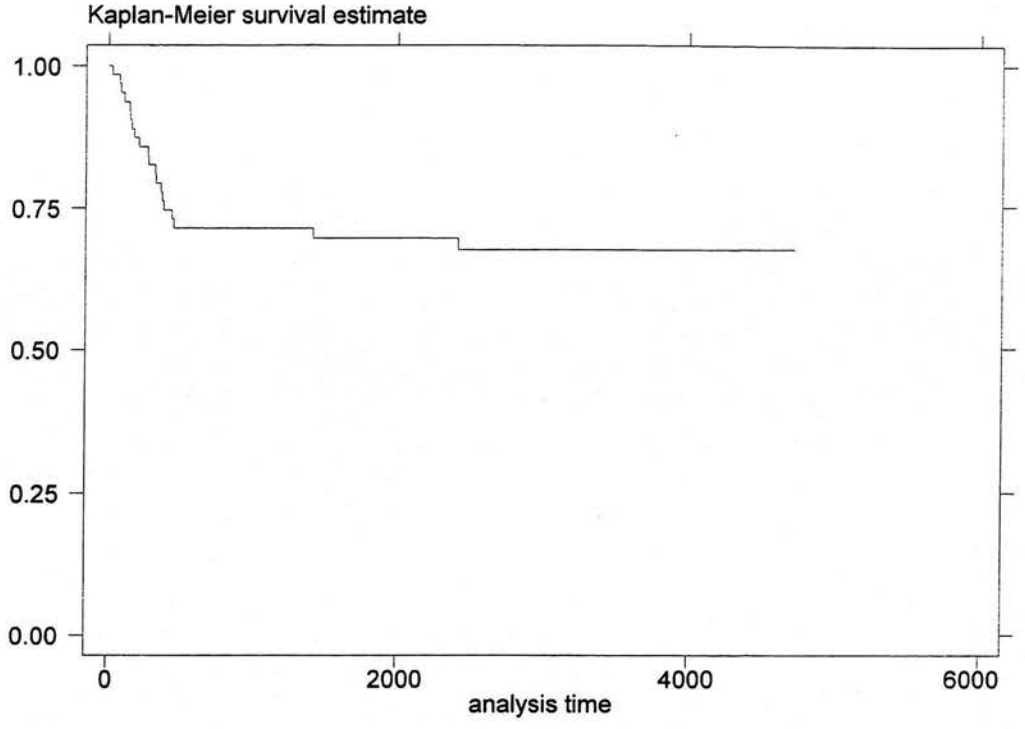


Figure A.9 Central Nervous System tumours

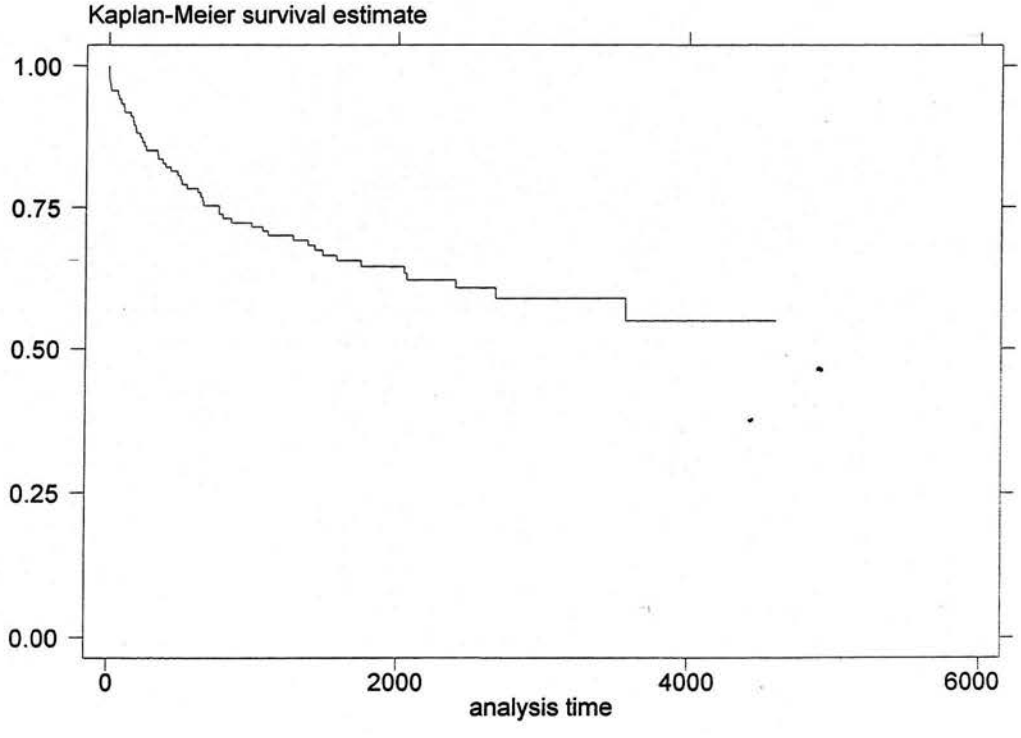


Figure A.10 Bone tumours

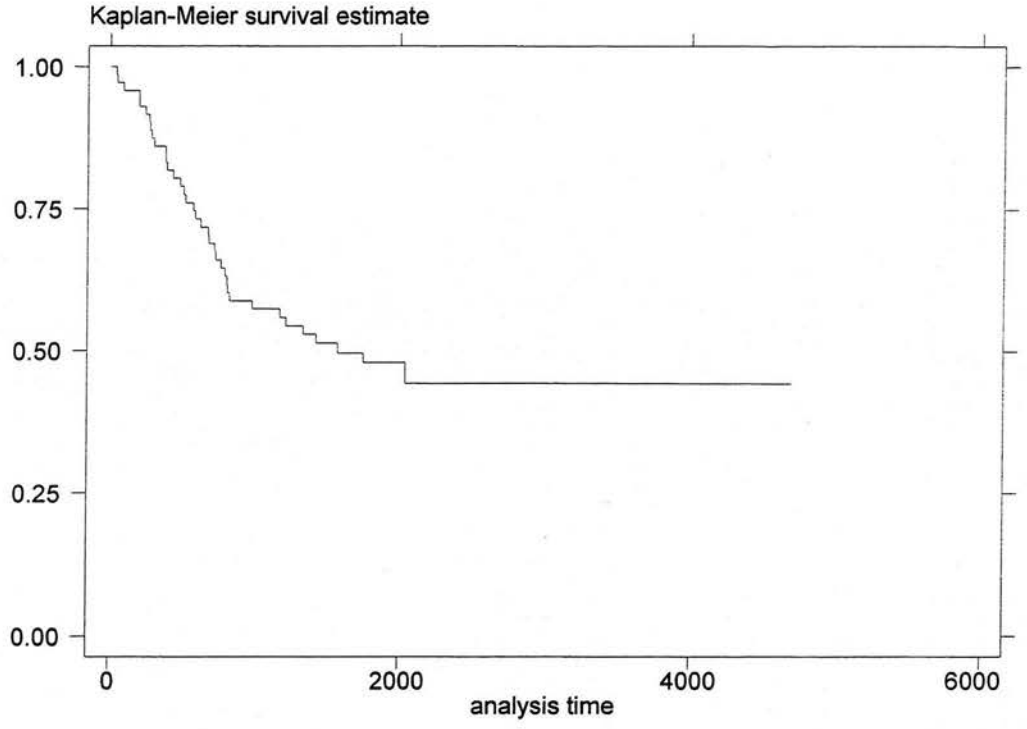


Figure A.11 Soft tissue sarcomas

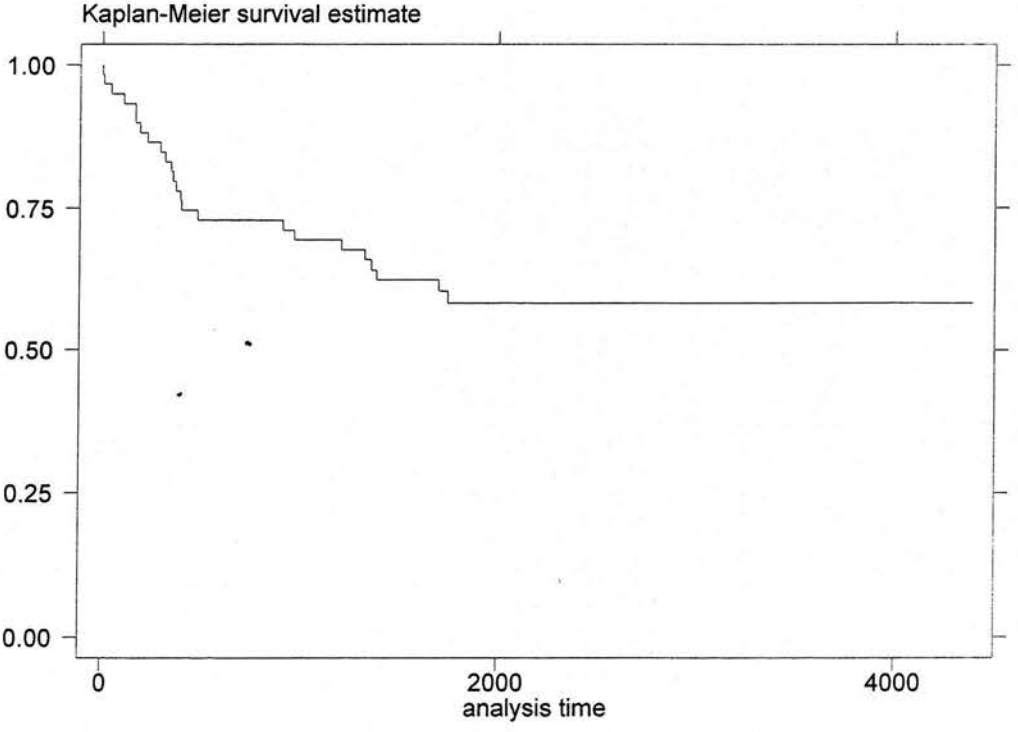


Figure A.12 Germ cell tumours

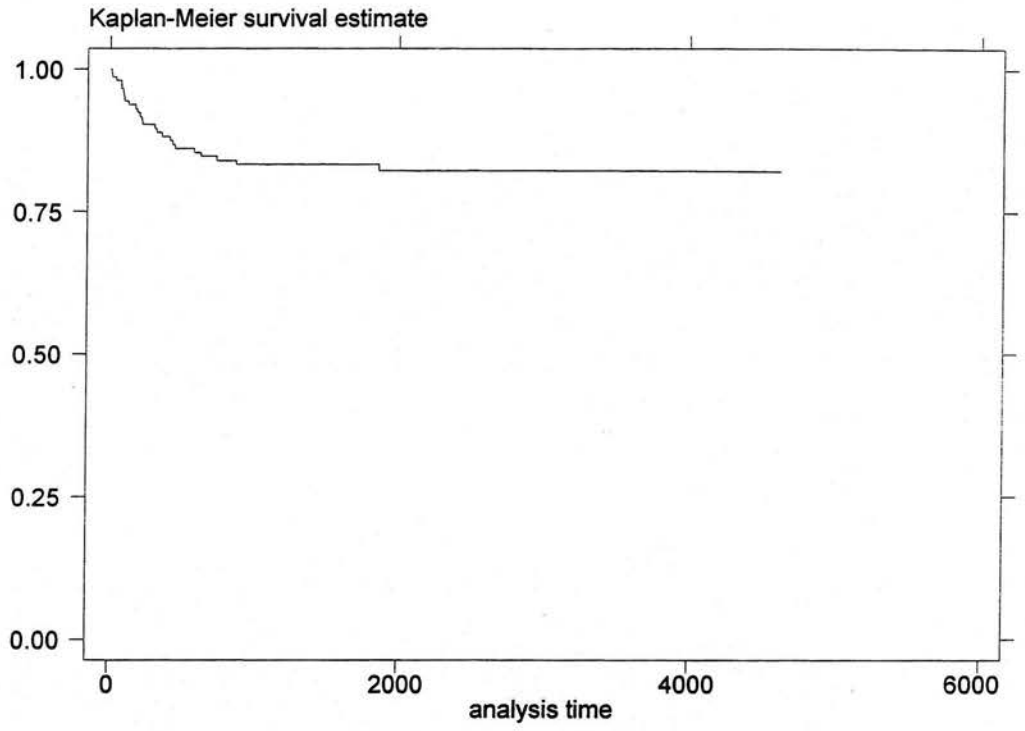


Figure A.13 Carcinomas

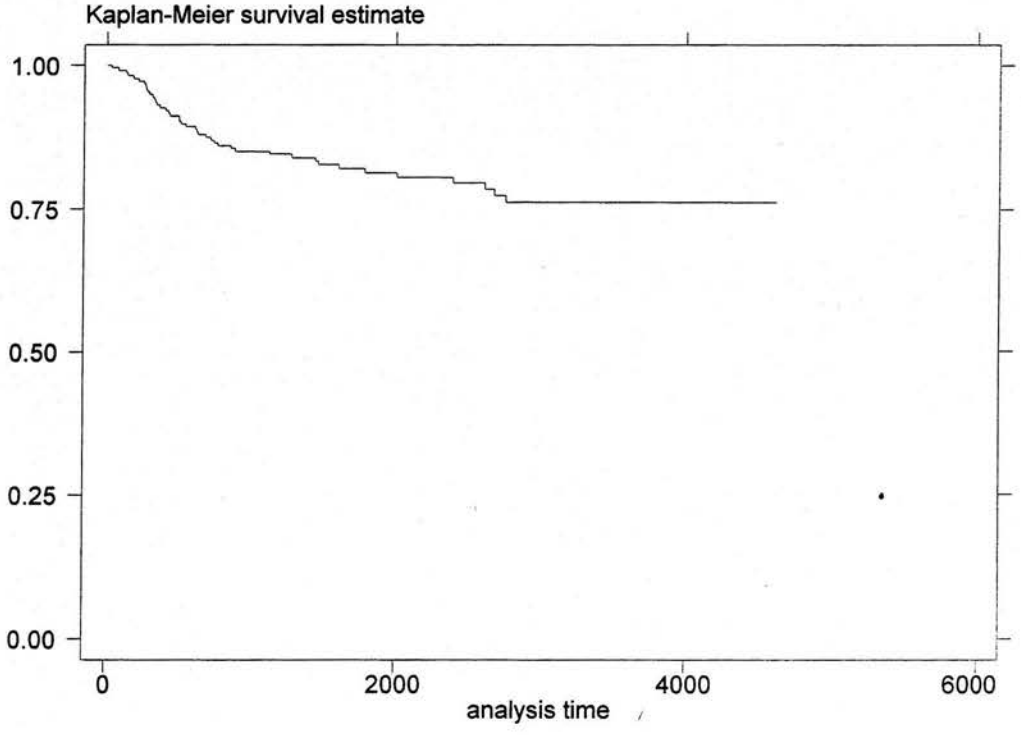


Table A1 Hazard Ratios of dying using multivariate Cox regression modelling by diagnostic group for sex, age, period of diagnosis, county of residence, size of treatment centre

Variable	All cancers	Leukaemias	AML	ALL	Hodgkin's Disease	Non Hodgkins Lymphoma	CNS Tumours	Germ Cell Tumours	Carcinomas
10-24 year olds									
Sex									
male	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
female	0.82	0.64	0.63	0.71	0.44	1.08	0.87	1.47	0.76
Age at diagnosis									
10-14	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
15-19	1.18	1.76	1.49	3.01	1.88	3.06	0.79	1.44	0.75
20-24	0.84	1.13	1.27	2.34	4.55	0.62	2.00	1.14	1.38
Period of diagnosis									
1985-1989	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
1990-1994	1.01	0.79	0.99	0.44	**1.11**	**2.88**	0.65	0.86	0.85
County of residence									
Northumberland	1.08	0.96	0.50	2.68	-	0.97	0.67	0.52	1.97
Tyne and Wear	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
County Durham	**1.42**	0.85	0.75	3.04	0.97	1.55	1.35	0.59	**2.60**
Teesside	1.35	1.43	0.65	**5.70**	0.82	2.31	1.27	1.14	1.70
Cumbria	1.00	0.46	0.27	1.30	0.68	2.03	1.38	0.89	2.02
Size of treating hospital									
Centre	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
District	0.67	1.14	0.57	1.21	0.64	1.05	14.50	0.27	0.63

Figures in bold = significant at 95% level

Table A2 Numbers of Patients in each categoryz

Variable	All cancers	Leukaemias	AML	ALL	Hodgkin's Disease	Non Hodgkins Lymphoma	CNS Tumours	Germ Cell Tumours	Carcinomas
10-24 year olds									
Sex									
male	550	75	20	47	95	40	80	100	61
female	486	57	18	33	81	23	57	43	154
Age at diagnosis									
10-14	186	44	7	35	19	11	41	9	23
15-19	333	55	19	31	61	22	38	31	54
20-24	517	33	12	14	96	30	58	103	138
Period of diagnosis									
1985-1989	538	64	21	41	93	44	69	74	105
1990-1994	498	68	17	39	83	19	68	69	110
County of residence									
Northumberland	81	12	5	6	10	4	8	12	14
Tyne and Wear	397	43	14	24	67	29	55	64	88
County Durham	182	34	7	22	32	13	27	19	34
Teesside	216	25	5	17	34	10	23	28	49
Cumbria	160	18	7	11	33	7	24	20	30
Size of treating hospital									
Centre	775	112	30	74	113	45	132	94	134
District	247	20	8	6	61	16	2	46	78

Table A3 Confidence limits of values shown in table A1

Variable	All cancers	Leukaemias	AML	ALL	Hodgkin's Disease	Non Hodgkins Lymphoma	CNS Tumours	Germ Cell Tumours	Carcinomas
10-24 year olds									
Sex									
male	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
female	0.65-1.04	0.37-1.11	0.30-1.32	0.20-2.47	0.18-1.12	0.40-2.88	0.48-1.58	0.57-3.80	0.39-1.48
Age at diagnosis									
10-14	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
15-19	0.85-1.62	0.93-3.34	0.68-3.23	0.56-16.23	0.21-16.99	0.80-11.76	0.33-1.88	0.27-7.67	0.22-2.53
20-24	0.61-1.14	0.56-2.79	0.44-3.58	0.30-18.01	0.56-36.69	0.14-2.82	1.00-4.00	0.22-6.03	0.46-4.11
Period of diagnosis									
1985-1989	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
1990-1994	0.96-1.13	0.45-1.39	0.46-2.11	0.10-1.86	0.42-2.91	1.03-8.03	0.35-1.20	0.38-1.96	0.44-1.63
County of residence									
Northumberland	0.69-1.69	0.35-2.62	0.11-2.30	0.43-16.45	0.00	0.11-7.90	0.15-2.91	0.07-4.02	0.63-6.11
Tyne and Wear	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
County Durham	1.03-1.94	0.43-1.74	0.30-1.83	0.53-17.31	0.30-3.15	0.45-5.43	0.62-2.94	0.13-2.65	1.03-6.57
Teesside	1.00-1.83	0.71-2.90	0.23-1.78	1.01-32.03	0.25-2.65	0.68-7.80	0.55-2.97	0.44-2.95	0.75-3.84
Cumbria	0.69-1.43	0.15-1.34	0.06-1.22	0.18-9.24	0.18-2.60	0.38-10.76	0.62-3.09	0.18-4.21	0.72-5.61
Size of treating hospital									
Centre	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00	1.00
District	0.49-0.91	0.55-2.38	0.13-2.50	0.27-5.38	0.23-1.78	0.83-1.33	2.61-80.72	0.71-1.00	0.29-1.34

Reference List

1. Cotterill S.J., Parker L., Malcolm A.J., Reid M., More L., and Craft A.W. Incidence and Survival for cancer in children and young adults in the North of England, 1968-1995: a report from the Northern Region Young Persons' Malignant Disease Registry. British Journal of Cancer 83[3], 397-403. 2000.

2. Kaplan E.S. and Meier P. Nonparametric estimation from incomplete observations. J Am Stat Assoc 53, 457-481. 1958.

CONSENT FORM

Study into the Needs of Young People with Cancer
(Patient)

		Please delete as applicable
1.	I have read the Information Sheet for patients.	Yes/No
2.	I have had the opportunity to ask questions and discuss the research study.	Yes/No
3.	I am satisfied with the answers to my questions.	Yes/No
4.	I have received enough information about this study.	Yes/No
5.	I have spoken to Dr/Mr/Ms.....	
6.	I understand that I am free to withdraw from the study at any time without giving a reason and without affecting my future care.	Yes/No
7.	I agree to take part in this research study.	Yes/No

Signature..... Yes/No

Name (block capitals).....

Date.....

Signature of witness.....

Name (block capitals).....

Date.....

FOCUS GROUP TOPICS

Non centre questions

1. How do you define adolescence?
2. Does it matter?
3. Do you ever look after young people with cancer in this unit, if so what is your experience of caring for them?
4. What sort of things are important for young people with cancer?
   a) Getting better?
   b) Being managed in a special centre
   c) Close to home
   d) Accessible for parents
   e) Accessible for friends
   f) Keeping up with education
5. Where would you be looked after if you had cancer?
6. What facilities do you think are needed for adolescents with cancer
7. What is the role of a hospital away from a large teaching centre in the management of adolescents with cancer?

FOCUS GROUP TOPICS

Patients' Questions

1. Can you describe what happened to you when you first became ill?
2. What were the good points, and what were the bad points of your treatment?
3. What causes most illness in young people?
4. How common is cancer -
   a) In adults
   b) In young people?
5. What sort of things are important for you, and how important are they?
   a) Getting better
   b) Being managed in a special centre
   c) Being close to home
   d) Being Accessible for parents
   e) Being Accessible for friends
   f) Keeping up with education
   g) Anything else?
6. Where would you have preferred to have been looked after with your illness?
7. What facilities would you like to see provided when adolescents with cancer are looked after?

FOCUS GROUP TOPICS

Healthy Adolescents Questions

1. Who can get cancer?
2. What causes most illness in young people?
3. How common is cancer -
   a) In adults
   b) In young people?
4. What sort of things are important if you or a close friend has cancer?
   a) Getting better?
   b) Being managed in a special centre
   c) Being close to home
   d) Being Accessible for parents
   e) Being Accessible for friends
   f) Keeping up with education
5. Where would you be looked after if you had cancer?
6. What facilities would you like to see provided when adolescents with cancer are looked after?

Study of Cancer in Young people and Adolescents - Questionnaire for Patients

Please could you fill this form in to give us some basic information about people attending these sessions. You will see that we have not asked for your name, and any information you provide will be held in the strictest confidence.

About you:

Age: _____ Sex: _____

Have you passed any public examinations, if so please can you tell us if you have any of the following.

No. of GCSE's _____ No. of A Levels _____

Other qualifications (please say what these are) _____

If you have left school, please tell us what your job is _____

Please could you write down the name of your diagnosis _____

Which hospitals have you attended with your current illness? (if so please say when and what for)?

_____

_____

Please could you write down the postcode of where you live. If you cannot remember it, just write down the name of the village or town where you live. _____

About your family:

Parents occupation:

Father _____ Mother _____

Do you have any brothers or sisters, if so how many?

Brothers _____ Sisters _____

Thank you for your help!

Study of Cancer in Young people and Adolescents - Questionnaire for Healthy Adolescents

Please could you fill this form in to give us some basic information about people attending these discussion groups. You will see that we have not asked for your name, and any information you provide will be held in the strictest confidence.

About you:

Age: _____ Sex:_____

Have you passed any public examinations, if so please can you tell us if you have any of the following.

No. of GCSE's_____ No. of A Levels_____

Other qualifications (please say what these are_____

_____

Are you normally fit and well? yes/no

Have you ever been admitted to hospital (if so please say when, where and what for)?

_____

_____

Please could you write down the postcode of where you live. If you cannot remember it, just write down the name of the village or town where you live. _____

About your family:

Parents occupation:

Father _____ Mother_____

Do you have any brothers or sisters, if so how many?

Brothers_____ Sisters_____

Thank you for your help!

Study of Cancer in Young People and Adolescents

INFORMATION SHEET FOR PATIENTS - INDIVIDUAL INTERVIEWS

This information is about a research project for which we are requesting your participation. Your decision to take part is entirely voluntary and if you do not wish to take part this will not affect your care in any way.

We are trying to find out what teenagers and their parents feel are important aspects of their care and where might be the best place to treat teenagers with cancer in the future.

We are asking if you would be willing to take part in a discussion with a doctor talking about your care. This would last up to 30 minutes and be held in the out-patient unit in Leeds shortly before or after you have seen your normal doctor. The conversation would be recorded to allow us to write up in detail, at a later stage, what was said. Anything that is said will not be connected to any particular individual.

Thank you for taking time to read this.

If you have any questions or queries please speak to either

Dr John Wilkinson (telephone number 01904 825238)
Or
Ms Sue Morgan (telephone number 0113 2066205)

Study of Cancer in Young People and Adolescents

INFORMATION SHEET FOR PARENTS OF STUDY PARTICIPANTS

This information is about a research project for which we are requesting your child's participation. Your decision to take part is entirely voluntary and if you do not wish to take part this will not affect your child's care in any way.

We are trying to find out what parents and their children feel are important aspects of their care and where might be the best place to treat teenagers with cancer in the future.

We are asking if you would be willing to allow your child to take part in a discussion group talking about their care. This would last up to 1½ hours and be held in the in-patient unit. The conversation would be recorded, to allow us to write up in detail, at a later stage, what was said. Anything that is said will not be connected to any particular individual. Participants would also be asked to complete a brief (anonymous) questionnaire about themselves and their family background.

We would like to carry several group discussions groups, one of parents and one of young people themselves. This would involve a group discussion of up to 8-10 people each. The discussion would be led by a doctor and would last between 1 and 1½ hours. The discussion would be recorded and later written up. Any comments made during the course of the discussion would be entirely anonymous.

Later in the year we would be interested in talking to some parents in person and if you would like to be involved, we would be grateful if you could let us know.

Thank you for taking time to read this.

If you have any questions or queries please speak to either

Dr John Wilkinson (telephone number 01904 825238)
Or
Ms Sue Morgan (telephone number 0113 2066205)

Study of Cancer in Young People and Adolescents

INFORMATION SHEET FOR PATIENTS

This information is about a research project for which we are requesting your participation. Your decision to take part is entirely voluntary and if you do not wish to take part this will not affect your care in any way.

We are trying to find out what young adults feel are important aspects of their care and where might be the best place to treat young people with cancer in the future.

We are asking if you would be willing to take part in a discussion group talking about your care. This would last up to about an hour and be held in the Teenage Cancer Unit, St James' Hospital, Leeds. The conversation would be recorded to allow us to write up in detail, at a later stage, what was said. Anything that is said will not be connected to any particular individual.

This would involve a group discussion of up to 5 people each, all current or previous patients on the ward. The discussion would be led by a doctor not involved in your care. The discussion would be recorded and later written up. Any comments made during the course of the discussion would be entirely anonymous. We will also be asking you to fill in a very short questionnaire about yourself and your family.

Thank you for taking time to read this.

If you have any questions or queries please speak to either

Dr John Wilkinson (telephone number 01904 825238)
Or
Ms Sue Morgan (via the ward or telephone 0113 2066205)

Study of Cancer in Young People and Adolescents

INFORMATION SHEET FOR PATIENTS (OUTPATIENTS)

This information is about a research project for which we are requesting your participation. Your decision to take part is entirely voluntary and if you do not wish to take part this will not affect your care in any way.

We are trying to find out what young adults feel are important aspects of their care and where might be the best place to treat young people with cancer in the future.

We are asking if you would be willing to take part in an interview about your care. This would last about 30 - 40 minutes and take place in the clinic. The interviews will be carried out by a doctor not involved in your care. The conversation would be recorded to allow us to write up in detail, at a later stage, what was said. Anything that is said will not be connected to any particular individual.

Any comments made during the course of the discussion would be entirely anonymous. We will also be asking you to fill in a very short questionnaire about yourself and your family.

Thank you for taking time to read this.

If you have any questions or queries please speak to either

Dr John Wilkinson (telephone number 01904 825238)
Or
Ms Sue Morgan (via the ward or telephone 0113 2066205)

Extract from focus group discussion held on the 22nd October 2000 at St James Hospital, Leeds.

Dr W Thank you very much. It's great of you to take part. What I'd like to talk about first is your experiences of how you were diagnosed. What actually happened when you were first ill and how that worked? So the early bit in terms of your early part of your illness and then talk about general things. So do you want to say how you found that?

P1 I had pain when I was sitting down and I went to the doctors. At first they just gave me some tablets to take the swelling down, then it was still there a week later, so I went back again and the doctor said you'd better go to the LGI for some scans and I went to LGI for scans. As soon as I turned up they decided to keep me in and in total I was in the LGI about 3 weeks before they actually knew what was wrong with me. I had a biopsy done and things like that. It took quite a while.

Dr W In terms of when you were taken ill and getting to hospital; how was that? Do you think it was OK?

P1 At first I didn't know what was wrong with me. When they said we're going to keep you in hospital and they didn't know what was wrong with me .....

Dr W How long ago was that?

P1 Beginning of May.

Dr W So it happened all very quickly?

P1 Yes.

Dr W In terms of getting referred up to the hospital. Did you think that worked OK, or were there any things that could have been better?

P1 I'd seen numerous doctors and the doctor who was going to treat me, his patients were over at St James', so they transported me over to St James', where I was on the adult ward at first and then I learned about this ward. I prefer this ward to other words.

Dr W What happened to you Darren?

P2 One night when I was at home my Dad noticed, we were having some supper, he noticed a big lump on my neck. I didn't notice it in the past, because my school shirt covered it up and it was a big, huge lump on my neck. My Dad started to feel it and as he pressed it I felt really faint and dizzy and my Dad opened the door and he sat me on the door step. He took me straight up to the hospital - that Dewsbury hospital. They kept me in and they decided to do a biopsy on my neck at the hospital.

Dr W So you didn't go to your GP at all; you went straight up to hospital?

P2 Um – Yeah, I did. That was before it was really big. It was small and I was complaining of tiredness.

Dr W So how long was it between you seeing your family doctor and that time you actually went up to hospital? When did you first see your family doctor?

P2 I saw my doctor and he just sent me home; said it's just a swelling. I went again and they sent me home again.

Dr W So how long was it roughly, not exactly, from the first time you went to when you went to hospital and they kept you in?

P2 About a week.

Dr W And how many times in that week had you been to see your GP?

P2 Twice and I was worried about what it was. I couldn't even imagine or dream that it was this. At first they thought it was glandular fever and it took them; and Dewsbury hospital - I thought they were quite slack - it took them about two weeks to refer me, but they didn't tell me. Dewsbury hospital knew what I had, but they didn't tell me 'cause they sent all the scan stuff and my biopsy results up here and then I came here and the first morning I came here I got told by Dr Lewis that I had .....

Dr W In Dewsbury had you seen a children's doctor or an adults' doctor? Do you know?

P2 I was on a children's ward and every single doctor in Dewsbury hospital saw me - every one! I had about five trainees on me as well. I had about seven main doctors, who came to see me - none of them knew what it was, and then they set trainees on me as well.

Dr W OK, thanks for that.

Dr W Akeem. What happened to you? What were your early experiences?

P3 I used to blow my nose, and get bleeding. He give me a spray. He said I had got an infection, I had a lot of swelling and before that the doctor said it was sinuses. I used to blow my nose and blood came out. I went 3-4 times to the doctor. I went to dentist with toothache.

Dr W So how did you eventually get to St James'?

P3 I got a nose bleed this side 5 o'clock, went to BRI and they just told me to go home and see my GP. So went home. At 6 o'clock it started bleeding again. Went back to hospital, did some tests. They talked to my mother. Took 3-4 hours. In afternoon started again.

Dr W So what happened from that time when you were having all the bleeding? When you were sent up to the hospital here.

P3 Four weeks, because I was there for two weeks and then they sent me to .....?

Dr W So, to get it straight: from having the initial bleeds, you were seeing your GP before that happened. After the bleeding started what happened then? You went up to the hospital?

P3 Four times, and the fourth time they took me in, kept me in the ENT department. On the following Tuesday they did a scan; on Friday an MRI scan; Wednesday did a biopsy – all that time I was in hospital. The following Monday the doctor came to see me and said it is very serious. He said it is spreading and could go to the brain, he said it was as bad as it can be.

P3 The doctor said it could be one of three things

1 ? tumour
2 brain tumour
3 ? tumour

Dr W So how long was it between you being perfectly well to actually being here?

P3 A good seven to eight months. Before I was having headaches for 4-5 months.

Dr W So if we take the time from when you went to see the doctor about it. What time would that be? First seeing your GP and getting into St James'?

P3 Six to seven months. Doctor said it was sinuses. My mother had sinuses before.

Dr W So you were all at some stage told about your diagnosis?

Yes, the doctor told me it.

Dr W So how important do you think it was to be told pretty straight about what was going on?

P1 I thought it was important. When the doctor told me same as Akeem, he laid it out flat, said this is very, very serious. It scared me when he said that. When they were on about radical surgery. It is serious, but it doesn't seem as serious as if he'd said I had a year to live or some'at.

P3 When I came here the doctors told .....

Dr W So it was painted a lot blacker to you before you came here?

P3 It shocked me.

Dr W But in your case it was painted fairly black to you?

P1 It was in the LGI when I found out they told me they had something to tell me that was very serious. But when I got here … other treatment.

Dr W So it was here when you saw Dr Lewis?

P1 Dr Picton I saw here.

P3 It's very hard. The treatment works.

Dr W So how do you feel in general about .....? What I'm going to ask really is some general issues about health in people of your age. How common do you think this is?

What's the most common thing that affects people of your age?

P1 Things like meningitis, that's passed easily round schools.

P2 Flus.

P1 Things you catch from other people - come into contact with.

Dr W You said cancer affects 1 in 3 which is absolutely right, but in people of your age any sort of idea?

P2 Haven't got a clue.

Dr W Would you say its common, rare, very rare or extremely rare?

P1 I'd say rare. I was the first in my school that got it.

So am I.

There's a thousand in my school ..... small percentage.

P2 It's just so unbelievable that it's you and not the other 900 that have got it.

Dr W So what we're going to talk about now is some of the things that are important to you and what actually matters as far as your care is concerned. We ran a little pilot study to try and identify some of the things that might be important and I'll just read out some of these. What I'd like to do is just talk to you about each of these and how important these factors are, and they're in this order: getting better (that's 1); being managed in a special centre (that's number 2); being close to home (number 3); being close for parents to visit; the next is being close for friends to visit; and the last thing is education and how important is that? For all of these if you want I'll show you the sheet. What, for you, are the most important out of getting better; special centre; close to home; parents; friends; education?

P2 I'd say getting better is first priority; then its education.

Well I think it's education, because I feel strongly about keeping up with school.

P1 Parents and visitors, treatment in specialist centres, then probably even.

Dr W You're from Dewsbury and you're from?

P1 Between Leeds and Bradford.

Dr W How far away from Bradford?

P1 About 15 to 20 minutes drive.

Dr W How far are you?

P2 About 40 minutes.

Dr W You're quite near.

Dr W So how important is being treated near to home as against all those other things?

P3 The further you are the more hard it is to travel.

Dr W If you put yourself in a situation of being, say, 50 miles away, what would be more important to you - being looked after in a specialist centre or being close to home, or being near to your parents?

P1 I think being looked after in a specialist centre.

P2 And your parents being there all the time.

Dr W Right.

The discussion continues.....

Column Structure of North Yorkshire Adolescents Data 1985-89 and 1990-94

The data is supplied in CSV format in the following structure.....

Column	Explanation
year	Year of registration
regno pat id	Patient Identifier
ward name	Ward of Patient Residence
sex	Sex - M or F
age	In years between 10 and 24
site	ICD9 Site Code
name	ICD9 Site Translation
type	ICD0 Type Code
name	ICD0 Type Translation
anniv date	Anniversary Date
trust1	Trust Code of 1st Hospital
trust2	Trust Code of 2nd Hospital
trust3	Trust Code of 3rd Hospital
trt op	Treatment by Operation - Y or N
trt rt	Treatment by R/T - Y or N
trt chem	Treatment by Chemotherapy - Y or N
trt horm	Treatment by Hormone Therapy - Y or N
death date	Death Date
dcause1	ICD9 1st Cause of Death Code
name	ICD9 1st Cause of Death Translation
dcause2	ICD9 2nd Cause of Death Code
name	ICD9 2nd Cause of Death Translation
dcause3	ICD9 3rd Cause of Death Code
name	ICD9 3rd Cause of Death Translation
dcause4	ICD9 4th Cause of Death Code
name	ICD9 4th Cause of Death Translation

Source of Document	Date C.D. Sent	
Cancer Registry No	Patient ID No	Ple
Surname		
Forename	Initial	Previous S
Address 1		Sex M F
Address 2		Date of B
Address 3		Birthplac
Postcode	NHS No	GP Initial
Hospital 1	Unit No 1	
Hospital 2	Unit No 2	
Hospital 3	Unit No 3	
Tumour Site		
Tumour Type		
Date 1st Symptom	Date 1st GP Referral	Date 1st Hospital Visit
Basis of Diagnosis 1 H, 2 CY, 3 O, 4 CL, 9 NK	Regional Nodes Y N U	Metastases Y N U
		Site of Me 0 Nodes
	Screening Y N U	Date of S
Date Op 1 N U	Surgery	
Date Op 2	Surgery	
Date RT 1	Radiotherapy	

N U	
Date RT 2	Radiotherapy
Other Treatments	
Date Chemotherapy N U	Date Hormone Therapy N U / Date Abla N L
Other Primaries 1 XR Code	Year / Cancer Registry No
Other Primaries 2 XR Code	Year / Cancer Registry No
Patient's Occupation	Patient's I
Husband's Occupation	Husband'
Father's Occupation	Father's li
Date of Death	Place of Death 1 Hospital 2 Home 3 Hospice 4 NH / Post Mort Y N
Cause of Death Ia	
Cause of Death Ib	
Cause of Death Ic	
Cause of Death II	

SIR JAMES SPENCE INSTITUTE

UNIVERSITY OF NEWCASTLE

Department of Child Health
The Royal Victoria Infirmary
Queen Victoria Road
Newcastle upon Tyne NE1 4LP

Our Ref: LP/AA

31st March 1998

Mr J Wilkinson
North Yorkshire Health Authority
Ryedale Building
4th Floor
60 Piccadilly
YORK
YO1 1PE

3 APR 1998

Dear John

I enclose for you, a disc containing the information we have available on database from the Northern Region Malignant Disease Registry. It differs from that you requested in the following respects:

1) Ward name is replaced by local authority at diagnosis.

2) First, second and third hospitals of treatment are replaced by referring and treating hospital.

3) Death cause coding is not on database.

If this information is insufficient for your needs, you are welcome to visit the registry and abstract any further information you may require.

Many thanks.

Yours sincerely

Dr Louise Parker
Senior Lecturer in Epidemiology
Children's Cancer Unit

Enc

Copy to: Professor AW Craft
Mrs L More

Direct Tel: 0191 202 3037
Direct Fax:0191 202 3060

Telephone · 0191 202 3033
Fax · 0191 202 3022

Filename - NYHA.XLS

Field	Description
DIAGYEAR	Year of Diagnosis
REGNO	Registration Number
PRIMARYNO	Primary Number
DLOCAUTH	Local Authority at Diagnosis (codes in LOCAUTH.XLS)
SEX	Gender
AGEATDIAG	Age at Diagnosis
SITE	Site
MORPHOLOGY	Morphology
DODDATE	Date of Diagnosis
REFHOSP	Referring Hospital (codes in HOSPITAL.XLS)
TH	Treating Hospital
DOFUDATE	Date of Last Follow Up
FOLLOWSTAT	Status at Last Follow Up (codes in STATUS.XLS)

PERGAMON

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Survival from adolescent cancer in Yorkshire, UK

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Abstract

The aim of this study was to investigate survival rates for adolescents with cancer and identify factors associated with differential long-term prognosis in Yorkshire, UK. A survival analysis of a population-based cohort of young adults aged 15–24 years, diagnosed with a malignancy in the former Yorkshire Regional Health Authority between 1985 and 1994 was carried out. The main outcome was death from all causes. Overall survival for the 1097 adolescents with a malignancy increased by 30% between 1985–1989 and 1990–1994 ($P=0.004$). This improvement was reflected in most subgroups of cancer. Large scale geographical differences in survival rates were observed across Yorkshire, with an increased risk of death in North Yorkshire and Humberside of 34% and 35%, respectively, compared with West Yorkshire. Small scale analyses showed reduced survival in areas of high population density, but no consistent trends were associated with socio-economic status. Improved survival from all cancers in young adults over the last decade is clearly seen. Reasons for differential survival by geographical area are unclear and warrant further investigation.

Keywords: Survival and cancer; Adolescent; Socio-economic status; Population density

1. Introduction

After road traffic accidents and suicide, adolescent cancer is the third most significant cause of mortality in young people in the United Kingdom. In 1993 in England and Wales, there were 375 deaths from cancer in the age range of 15–24 years [1].

Cancer in adolescence differs from that in adults and children: cancer in children is usually caused by a range of developmental tumours, whereas in adults the commonest type of cancer is epithelial in nature (e.g. breast, lung and prostate). Adolescent cancers tend to be a mix of paediatric and adult cancers. Although ICD10 has been used to categorise malignancies in children, this classification scheme is not without its problems when applied to the adolescent and young adult age groups.

Various studies have looked at adolescence in relation to cancer, yet the age range examined has differed quite markedly. For example, Fritschi [2] looked at the incidence of cancer amongst New South Wales adolescents and concentrated principally on the appropriate classification scheme in a study of adolescents aged 10–19 years with cancer between 1972 and 1991. The authors concluded that the childhood classification scheme is appropriate to describe cancer incidence in adolescent age groups, but perhaps requires minor modifications. The classification used in this study was therefore the International Childhood Classification of Cancer (ICCC) [3], which uses tumour morphology as well as tumour site.

The biology of malignant disease largely determines the age groups to be analysed and for the purposes of this study, adolescence was defined as between 15 and 24 years of age. Over the past 20 years, almost all of the care of young children with cancer has been centralised in the regional centres. This has not happened to the same extent with adolescents. The approach to the treatment of adolescents is not directly age-related, but in Yorkshire varies with hospital and with diagnosis. In the more common malignancies in this age group, treatment is more likely to take place at a local level than in young children.

In 1999, Stiller and colleagues [4] examined patterns of care and survival in people with acute leukaemia

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between the ages of 15 and 29 years. They concluded that survival had improved over the 10-year study period in the 15–19 year old group, that survival rates were similar at teaching and non-teaching hospitals, and that entry into trials had a significant beneficial effect on survival. Apart from this article, there is little in the literature discussing the association of risk factors with survival of adolescents and young people from all cancers either in the UK or elsewhere. This study therefore analysed data on all malignancies diagnosed in the age range 15–24 years occurring in Yorkshire in the UK, to determine whether there is a need for a more centralised approach in the management of adolescent cancer services.

Patients and methods

The geographical area of Yorkshire, UK has a total population of 3.7 million and encompasses a wide variation of urban and rural environments with accompanying differences in deprivation and population density. A survival analysis was performed on a dataset containing 1097 cases aged 15–24 years, diagnosed in Yorkshire (Fig. 1) between 1 January 1985 and 31 December 1994 and followed-up until 1 January 1998. There were approximately 0.5 million people living in Yorkshire aged 15–24 years in 1991 (The 1991 Census, Crown Copyright, ESRC purchase).

Cases were extracted from a population-based register of malignancies based at the Northern & Yorkshire Cancer Registry and Information Service (NYCRIS). In common with all cancer registries, NYCRIS goes to extensive lengths to ensure completeness of data capture. One of the main strengths of cancer registration is the multiplicity of sources of notification [5]. In the Northern and Yorkshire Region, trained peripatetic clerks from NYCRIS regularly visit all hospitals in the region. Notifications are usually instigated through copies of the pathology forms being forwarded to NYCRIS. Haematological malignancy data are collected through the haematologists. All cases of cancer are flagged at the National Health Service Central Registry in Southport, so that in the case of a non-malignant cause of death, the registry is notified. Copies of death certificates are forwarded to the cancer registry, and therefore we can be confident that details of cases are accurately captured and that death data is fully captured by this system.

The national core contract for cancer registration lays down standards for completeness, accuracy and timeliness in the collection of the minimum dataset [6]. These minimum standards are all being achieved by NYCRIS.

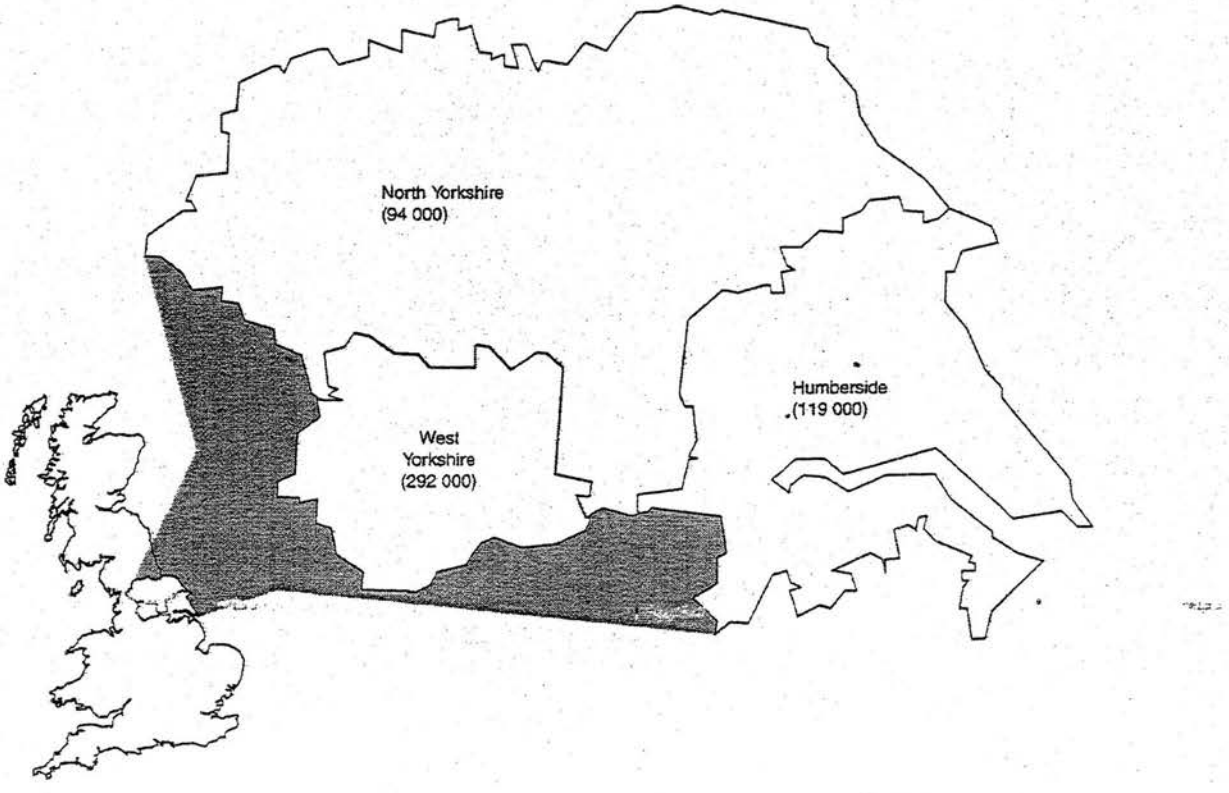


Fig. 1. A map of the former Yorkshire Regional Health Authority by county (populations aged 15–24 years).

Cancers were coded and categorised into the 12 major diagnostic groups detailed in Table 1 according to the CCC [3], which is based on Birch and Marsden's cheme [7]. The end-point of interest was death from ny cause, with date of diagnosis acting as the time-ori-in. For each diagnostic group/subgroup, the following ariables were investigated:

- Gender (male or female).
- Age (in years) at diagnosis (15–19, 20–24).
- Period of diagnosis (1985–1989, 1990–1994).
- County of residence at diagnosis (West Yorkshire, Humberside, North Yorkshire).
- Socio-economic status (Carstairs index [8] from the 1991 census (1991 Census, ESRC Publication Crown Copyright) — based on address at diagnosis).
- Person-based population density (ppd) (1991 Census) divided into thirds.
- Chemotherapy treatment (yes/no) for leukaemias only, was adjusted for in the analysis (result not shown).

Individuals were assigned a deprivation score as a roxy for socio-economic status, based on the validated ostcode of their address at diagnosis using the follow-ıg census variables to calculate the Carstairs index — ercentages of unemployed male residents over 16 years, esidents in social class 4 and 5, non-car ownership and vercrowding. Each address was linked to its census electoral ward (EW) ($n=532$) via the central postcode directory. The Carstairs index was categorised into five equal groups of the entire study population, with scores ranging from −4.95 (most affluent) to 17.63 (least affluent).

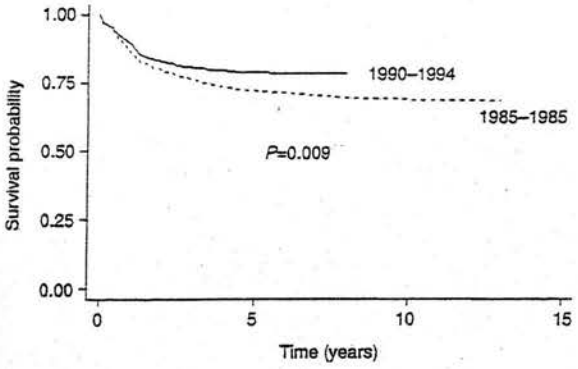
Ppd at EW level was used as a proxy for urban/rural status: firstly, area-based population density was calculated by dividing the population in each enumeration district (ED) by its area in hectares. Ppd was then obtained by aggregating the population-weighted average of area-based population density in each ED to an EW. This measure more accurately reflects the density at which the average person in any geographical area lives than the classic area-based measure [9]. Ppd was categorised into three groups, and was defined as low (<35.7 persons/ha), medium (35.7–52.6 persons/ha) and high (>52.6 persons/ha).

Survival rates were calculated using Kaplan–Meier methods [10]. Initially, ppd was investigated separately using the log-rank test to assess whether survival differed for each diagnostic group. The data were then modelled using Cox's proportional hazards technique [11]. Hazard ratios (HR) and the level of significance (5%) were reported. HR are the ratio of the hazards (probability of dying at time t, having survived to that time) for two different values of a covariate, and can be interpreted in a similar way to relative risks. The level of significance was set at 5%, with a P value of 0.05 or less indicating a statistically significant effect, for compara-

able 1
requency of cancers by diagnostic group and numbers of deaths of children and young adults (15–24 years) diagnosed between 1985 and 1994

CCC group[a]	Diagnostic group	Cases n (%)	Deaths n (% of cases)
-12	All cancers[b]	1097 (100)	289 (26)
	Leukaemia[b]	84 (8)	53 (63)
1a	Acute lymphoblastic leukaemia	43	24 (56)
1b	Acute myeloid leukaemia	34	22 (65)
1c–1e	Other leukaemias	7	7 (100)
	Lymphomas	276 (25)	47 (17)
2a	Hodgkin's disease (HD)[b]	206	26 (13)
2b–2e	Non-Hodgkin's lymphoma (NHL)[b]	70	21 (30)
	Central nervous system (CNS) tumours[b]	129 (12)	43 (33)
	Sympathetic nervous system tumours	11 (1)	7 (64)
	Retinoblastoma	0	0
	Renal tumours	6 (0.5)	2 (33)
	Hepatic tumours	2 (0.2)	2 (100)
	Malignant bone tumours	46 (4)	23 (50)
	Soft-tissue sarcomas	58 (5)	21 (36)
0	Germ cell tumours[b]	162 (15)	27 (17)
1	Carcinomas[b]	295 (27)	60 (20)
1a	Adrenocortical carcinoma	0	0
11b	Thyroid carcinoma	44	0
11c	Nasopharyngeal carcinoma	6	4 (67)
11d	Malignant melanoma	96	14 (15)
11e	Skin carcinoma	52	1 (2)
11f	Other and unspecified carcinomas	97	41 (42)
2	Other and unspecified malignant neoplasms	28 (3)	4 (14)

[a] International Classification of Childhood Cancer [3].



ig. 2. Kaplan–Meier survival curve by period of diagnosis for all ıncers diagnosed between 1985 and 1994.

ility with Stiller and colleague's results [4]. HR for each ıctor were calculated adjusting for all the other factors, ithin each diagnostic group. The proportional azard's assumption appeared to be valid.

. Results

Table 1 describes the number of cases and deaths for ıe diagnostic groups, and those which have a sufficient umber of deaths to enable a multivariate analysis to be erformed. Cases with leukaemia had by far the largest roportion of deaths (almost two-thirds died), whilst a xth or less of the cases with germ cell tumours and lodgkin's disease (HD) died. The carcinomas comrised a mixed group of malignancies including melaomas ($n=96$, 33%), thyroid ($n=44$, 15%), skin $=52$, 18%) and other ($n=103$, 35%).

Overall survival rates were 87.7, 81.0 and 75.2% at 1)5% CI: 85.6–89.5), 2 (95% CI: 78.6–83.2) and 5 (95% I: 72.6–77.7) years, respectively. There was a sigificant improvement in survival from all cancers comined for adolescents diagnosed in 1990–1994, ompared with those diagnosed in 1985–1989 (Fig. 2), ith a considerable improvement at 1, 2 and 5 years fter diagnosis. This effect was consistent across all ıree counties.

Table 2 lists the proportion of deaths within each ppd category, by diagnostic group. Although there was no significant evidence of trend in the proportion of deaths across the categories of ppd for any diagnostic group, there was a suggestion that higher ppd was associated with a higher rate of death for all malignancies and carcinoma. (Carcinomas are presented as a single group, as two-thirds of deaths occurred in the 'Other and unspecified' category.)

Table 3 gives the number of cases for each variable and diagnostic group included in the regression analysis. The results of the multivariate regression are presented in Table 4. Between 1985–1989 and 1990–1994, survival improved by 30% overall ($P=0.004$), and this effect was present throughout all diagnostic categories, apart from leukaemias. However, both acute lymphoblastic (ALL) and acute myeloid leukaemia (AML) separately confirmed this finding (data not shown).

The most striking feature of the data is the consistent increased risk of death in Humberside and North Yorkshire compared with West Yorkshire across most of the diagnostic groups. This is not explained by socioeconomic status or population density. The overall significant increase of death of 45% in Humberside ($P=0.009$) and 34% in North Yorkshire is reflected most strongly in adolescents with leukaemia: here, the risk of death in North Yorkshire and Humberside is almost 2.5 times as great. This pattern was also observed for germ cell tumours. A survival curve displaying the significant differences across the three counties of Yorkshire is given in Fig. 3. No significant differences could be demonstrated in the case mix between the three counties in the study.

Further inspection of the data for leukaemia revealed that 90% of patients living in West Yorkshire and North Yorkshire at the time of diagnosis had chemotherapy, compared with only 74% of patients living in Humberside. However, this difference in treatment did not explain the poorer survival in Humberside, because we included a binary variable indicating whether or not chemotherapy was given for leukaemia. Similarly, by including a variable for chemotherapy for all cancers,

able 2
rends in survival by person-based population density and diagnostic group

CC group[a]	Diagnostic group	Cases	Population density			Test of trend P value
			Low	Medium	High	
-12	All cancers	1097	23.8	25.9	29.4	0.14
	Leukaemias	84	54.6	77.8	57.1	0.35
ı	Hodgkin's disease (HD)	206	12.1	12.9	12.7	0.99
>–2e	Non-Hodgkin's lymphoma (NHL)	70	28.6	20.0	40.9	0.26
	Central nervous system (CNS) tumours	129	29.6	27.9	42.9	0.17
)	Germ cell tumours	162	13.6	19.3	17.4	0.66
l	Carcinomas	295	15.9	21.1	23.2	0.44

[a] International Classification of Childhood Cancer [3].

able 3
requency of cancers by diagnostic group for gender, age and period of diagnosis, county, socio-economic status and population density

ariable	All cancers	Leukaemias	Hodgkin's disease	Non-Hodgkin's lymphoma	CNS[a] tumours	Germ cell tumours	Carcinoma
	n (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)	*n* (%)
	(*n*=1097)	(*n*=84)	(*n*=206)	(*n*=70)	(*n*=129)	(*n*=162)	(*n*=295)
ender							
Male	539 (49)	45 (54)	102 (50)	45 (64)	69 (53)	130 (80)	83 (28)
Female	558 (51)	39 (46)	104 (50)	25 (36)	60 (47)	32 (20)	212 (72)
ge at diagnosis (years)							
15–19	408 (37)	44 (52)	85 (41)	39 (56)	53 (41)	44 (27)	74 (25)
20–24	689 (63)	40 (48)	121 (59)	31 (44)	76 (59)	118 (73)	221 (75)
eriod of diagnosis							
1985–1989	575 (52)	43 (51)	110 (53)	38 (54)	66 (51)	88 (54)	144 (49)
1990–1994	522 (48)	41 (49)	96 (47)	32 (46)	63 (49)	74 (46)	151 (51)
ounty of residence							
West Yorkshire	615 (56)	41 (49)	117 (57)	35 (50)	78 (60)	98 (60)	161 (55)
Humberside	278 (25)	23 (27)	52 (25)	16 (23)	31 (24)	45 (28)	78 (26)
North Yorkshire	204 (19)	20 (24)	37 (18)	19 (27)	20 (16)	19 (12)	56 (19)
arstairs index							
1 — most affluent	220 (20)	11 (13)	43 (21)	19 (27)	25 (19)	33 (20)	47 (16)
2	216 (20)	16 (19)	40 (19)	12 (17)	33 (26)	28 (17)	61 (21)
3	219 (20)	22 (26)	42 (20)	11 (16)	19 (15)	36 (22)	68 (23)
4	215 (20)	16 (19)	41 (20)	12 (17)	27 (21)	36 (22)	53 (18)
5 — least affluent	227 (21)	19 (23)	40 (19)	16 (23)	25 (19)	29 (18)	66 (22)
opulation density							
Low	366 (33)	22 (26)	66 (32)	28 (40)	44 (34)	59 (36)	88 (30)
Medium	367 (33)	27 (32)	85 (41)	20 (29)	43 (33)	57 (35)	95 (32)
High	364 (33)	35 (42)	55 (27)	22 (31)	42 (33)	46 (28)	112 (38)

[a] Central nervous system.

urvival differences remained between the counties and opulation densities.

For socio-economic status and survival, a non-sig-ificant dose response was present in the carcinoma roup. Those in the least affluent groups were twice as kely to die compared with the most affluent. The umbers of deaths were insufficient to sub-categorise iis heterogeneous group of malignancies.

The significant increased risk of death in areas of igher population density ($P=0.024$) was independent f all other factors, including socio-economic status. he risk associated with population density appeared cross all diagnostic groups (apart from HD and high vels of ppd for leukaemia). For leukaemia, including LL and AML, germ cell tumours and carcinomas reas of medium levels of ppd conferred the highest risk.

Finally, Table 5 shows the number of patients treated y each consultant dealing with patients in this age roup over the period of the study. A total of 407 con-ultants were engaged in the care of adolescents in this ge range with cancer. In this 10-year period only 40 onsultants (10%) treated 10 or more patients, and lmost 75% dealt with less than 5 patients. With the xception of one neurosurgeon, all the consultants reating more than 10 patients were based in the regio-al cancer centre in West Yorkshire. The data presented in Table 5 was derived from aggregate data held by NYCRIS. We were therefore unable to include a variable in the Cox regression directly related to patient accrual. In a separate analysis, we did produce a model including the size of treating hospital (as registered with NYCRIS): this had no effect on the risk of death, nor did it make any difference to the hazard ratio estimates for the other variables included in the model (data not shown).

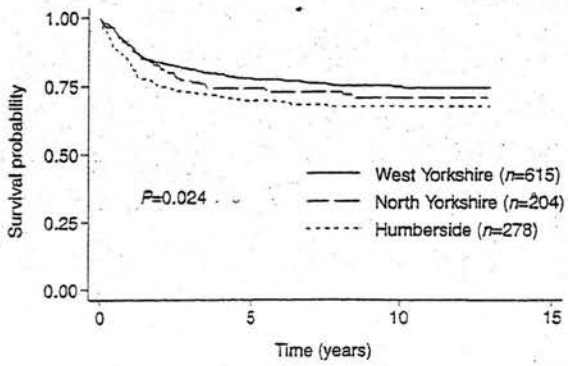


Fig. 3. Kaplan–Meier survival curve by county for all cancers diagnosed between 1985 and 1994.

able 4
azard ratios of dying using Cox regression analysis by diagnostic group for gender, age and period of diagnosis, county, socio-economic status and opulation density[a]

ariable	All cancers	Leukaemias	Hodgkin's disease	Non-Hodgkin's lymphoma	CNS[b] tumours	Germ cell tumours	Carcinoma
ender							
Male	1.00	1.00	1.00	1.00	1.00	1.00	1.00
Female	0.91	0.55	1.00	6.19**	1.14	2.16	0.57*
ge at diagnosis (years)							
15–19	1.01	0.45*	1.04	1.32	0.86	0.48	0.64
20–24	1.00	1.00	1.00	1.00	1.00	1.00	1.00
riod of diagnosis							
1985–1989	1.00	1.00	1.00	1.00	1.00	1.00	1.00
1990–1994	0.70**	1.06	0.65	0.30*	0.84	0.46	0.67
unty of residence							
West Yorkshire	1.00	1.00	1.00	1.00	1.00	1.00	1.00
Humberside	1.45**	2.43*	0.86	1.49	1.33	5.62**	1.39
North Yorkshire	1.34	2.40*	0.30	1.59	0.76	2.88	1.11
rstairs index							
1 — most affluent	1.00	1.00	1.00	1.00	1.00	1.00	1.00
2	1.13	1.75	0.85	1.03	0.77	4.33*	1.62
3	0.63*	0.74	0.77	0.25	1.09	0.84	1.15
4	0.79	1.59	0.72	0.36	0.31	3.19	2.28
5 — least affluent	0.94	2.04	0.82	0.37	0.40	1.49	2.06
pulation density							
Low	1.00	1.00	1.00	1.00	1.00	1.00	1.00
Medium	1.37	2.21	0.83	1.70	1.28	3.30*	1.15
High	1.60*	0.83	0.92	7.75*	3.21*	1.34	1.08

Significant at $*P < 0.05$, $**P < 0.01$.
[a] Hazard ratios are mutually adjusted for all other factors (i.e. gender, age, period, county, Carstairs index, population density, and chemotherapy treatment (Yes/No) for leukaemia).
[b] Central nervous system.

Discussion

There have been a number of attempts to produce a ndard definition of adolescence. It is inevitably an distinct concept and varies from individual to indivi- al. There is no universally accepted age limit for olescents and most would agree that no individual uld be considered an adolescent outside the age range 10–25 years, but within that age range, many differ- age criteria are used. The World Health Organiza- n defines adolescents as being aged between 10 and 19 years [12]. Other studies on adolescents, some of which are described later, consider a different age range. For example, Jamison [13], in his study of the psychological impact of cancer in 1985, used the age range 12–18 years. Enskär and colleagues [14], in a study which looked at 10 adolescents with cancer, used the age range 13–20 years.

The differing types of cancer combined with the specific needs of adolescence mean there is currently a debate on how adolescent cancer should be managed. This debate centres around whether it should be centralised in an adolescent cancer unit, as set out in the Calman-Hine Report [15], or as a less centralised model which, for example, would avoid the disadvantages for patients living in rural areas [16]. Currently, there are around 20 adolescent cancer units in the UK. The proposal to create an adolescent cancer unit in Yorkshire was the stimulus for this review.

The strength of this study is that it has examined data based on an appropriate classification scheme. Making direct comparisons with other work is difficult because of the inconsistent use of age groups. However, this study has concentrated on the 15–24 year olds, a group on which little has been reported in the past. The

ble 5
mber of consultants treating individual patients aged 15–24 years in Yorkshire Region between 1985 and 1994

ients treated	Number of consultants	%
	159	39.1
	139	34.2
	69	17
19	24	5.9
29	5	1.2
	11	2.7
	407	100.0

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